Learning the lessons: a multi-method evaluation of dedicated community-based services for people with personality disorder

Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R&D (NCCSDO)

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Glossary

'Dedicated' services
We use the phrase 'dedicated personality disorder service' to describe services such as the 11 pilots which focus exclusively on the needs of people with personality disorder (PD). We used this in preference to 'specialist service', because many other services, especially departments of psychology and psychotherapy, work extensively with people with PD and often have considerable specialist expertise in this area.

Direct and indirect service provision
In addition to delivering 'direct' services to service users, each pilot service undertook to work with other local agencies to provide support and training on PD. Throughout this report we refer to this aspect of their work as 'indirect service provision'.

Interventions
The 11 pilot services provided a broad range of different services to users including general support and advice, psycho-education, and specific social, occupational, psychological and medical interventions. We have used the word 'intervention' to refer to any form of service they provide, and the word 'therapy' to refer to formal structured psychological and psychotherapeutic interventions.

Personality disorder (PD)
People with a PD have *'enduring patterns of inner experience and behavior that deviate markedly from cultural expectations'* (American Psychiatric Association, 1994). Methods for classifying personality disorders include those based on groups or 'clusters' of personality traits and those based on the severity. Both are referred to in this report. There are three 'clusters' of PD: cluster A (characterised by social distance and eccentricity); cluster B (flamboyance and emotional instability); and cluster C (in which anxiety, perfectionism and a tendency to worry predominate). Classification based on severity distinguishes 'simple personality disorder' in which there are significant problems associated with disturbance in only one cluster, and 'severe PD' in which there is disturbance in more than one cluster with severe disruption both to the individual and to others.

'Pilot' service
When the 11 services we evaluated were commissioned they were referred to as 'pilot' services to signify that they were being funded for a limited period to test whether they could form the basis for a viable service. Since then several have moved on to become an integral component of local services and are therefore no longer 'pilots'. However, in this report we have retained the phrase pilot to refer to the 11 services that were originally funded and we were asked to evaluate.

Service users
Service providers used a range of different terms to refer to the people they work with including: 'client', 'service user', 'member' and 'patient'. The word they most commonly used was 'client'. Members of our Project Advisory Group stated that they preferred the term 'service user'. The terms 'client' and 'service user' are used interchangeably in the remainder of this report.

Tiered services
National recommendations on services for people with PD have been categorised as a series of tiers, ranging Tier 1 support for general services, Tier 2 outpatient services, Tier 3 intensive services (such as day services and case management), Tier 4 specialist inpatient services, Tier 5 secure and forensic services and Tier 6 residential units for people with Dangerous and Severe Personality Disorder.

Acronyms

We have endeavoured to use acronyms sparingly in this report, and to define each before using it in the text. However, we sometimes employed commonly used acronyms including:

ASPD - Antisocial Personality Disorder

BME - Black & Minority Ethnic

BPD - Borderline Personality Disorder

CBT - Cognitive Behaviour Therapy

CJS - Criminal Justice System

CMHT - Community Mental Health Team

CPA - Care Programme Approach

CPN – Community Psychiatric Nurse

DBT - Dialectical Behaviour Therapy

ED - Emergency Department – sometimes referred to as A&E

FTE - Full time equivalent

NIMH(E) - National Institute for Mental Health (England)

NSF - National Service Framework

PCT - Primary Care Trust

PD - Personality Disorder

SAP-AS- Standardised Assessment of Personality – Abbreviated Scale

SFQ - Social Function Questionnaire

SU - Service User

TC - Therapeutic community

XBX - 'expert by experience', a service user employed to help develop or deliver services

Identity of pilot services and study participants

In Appendix A we provide a detailed description of each of the 11 pilot services. Service leads consented to their service being named in these case studies and were given an opportunity to comment on a draft version. In the other sections of the report we have generally not referred to the pilots by name, but have described the kind of service they provided. We decided not to include views of referrers and commissioners of local services in the case studies because of the small numbers involved. We were concerned that their views might not be representative. Instead we have placed these data in Section 4.2 of the report in an attempt to reflect the diversity of their views.

In Section 5 we have not named the pilots but referred to each by a number and given a brief description of the service it provides. We did this at the request of some of the pilots who were concerned that these data provide an incomplete account of the work they have done and may not reflect current levels of service activity. While acknowledging that the limited number of services means that it may be possible to identify them, we agreed not to name them in this section of the report. Again we gave services an opportunity to examine these data in order to identify errors or omissions.

In order to protect the identity of individual participants we simply referred to 'staff', 'service users' and 'managers' in the case studies. In Section 4 we have provided a code for each of the participants based on their being a commissioner (C), referrer (R), service user (SU), carer (Carer), manager (M), or other member of staff (S). We have used the acronym FGSU to refer to quotes from service users from focus groups.

Acknowledgements

Project Advisory Group Members

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The Report

Executive Summary

Background

Personality disorders (PD) are important conditions that have significance for the individual, their family, and society at large. It is estimated that 4% of people in Britain have a PD. People with a PD have an enduring pattern of inner experience and behaviour that deviates markedly from cultural expectations. They are more likely to experience mental illness, substance misuse and social problems and the rate of suicide is seven times higher among people with PD. Some forms of personality disorder are characterised by quick-temperedness and impulsivity and levels of PD are far higher among those in contact with criminal justice services.

Concerns have been expressed about the quality of services for people with personality disorder. Many working in mental health and social care feel they are unable to help people with PD and some believe that they should not be offered a service. Service users report being dissatisfied with existing services and many believe that the treatment they received deteriorated as a result of being given this diagnosis.

As part of their response to these concerns, the Department of Health funded 11 dedicated community-based pilot services for people with PD in England. While evidence has begun to emerge showing that psychological interventions can benefit people with PD, little is known about the most effective way to deliver these. The role that dedicated services can play in supporting the work of others in health and social care is also unclear.

Aims

To evaluate the 11 pilot community services and capture lessons learned during the initial phase of their development. In order to achieve these aims we set out to:

- describe the organisational form, activity and function of 11 pilot services
- compare aims and objectives of services with those they actually deliver

- measure health, social function and service utilisation among a sample of people referred to these services

- identify organisational, therapeutic and other factors that service users and providers believe result in high-quality care for people with personality disorder.

Methods

A multi-method study comprising: (a) an organisational evaluation examining the context, form, and function, of the 11 pilot services; (b) a user-led qualitative evaluation of service users' and carers' views and experiences; (c) a cohort study examining demographic and clinical characteristics of a sample of those referred to the services; and (d) a Delphi study examining the level of consensus among expert authors, service users and providers about key aspects of the organisation and delivery of dedicated services for people with PD.

a. Organisational evaluation

Documentary evidence from each of the 11 pilot services was examined and in-depth interviews conducted with managers and front-line workers. We interviewed a range of staff delivering different aspects of each service using a topic guide specifically developed for the study. Interviews were conducted on at least two occasions. Data were audio recorded and verbatim transcripts made. Data were analysed using a grounded approach in order to generate a thematic framework which addressed study aims.

b. User-led qualitative study

Service user researchers were trained and provided with ongoing support to interview a sample of users and carers at each of the pilot sites. The sample was selected purposively in order to include both current and former service users and ensure that age, gender, component of service used and length of contact with the service were broadly similar to the mix of users at each service. Interview schedules were developed in consultation with the project Advisory Group and on the basis of previous literature on the subject. Data were audio recorded and verbatim transcripts were analysed by researchers trained and supervised in a qualitative framework-based approach.

c. Cohort study

In collaboration with service leads at each of the 11 pilot services a 'care pathway record form' was developed and used to record basic demographic data on a sample of those referred to each service. The form included information on the assessment process, the services which users were offered and those they received. We also asked pilots to incorporate three short questionnaires into their existing assessment procedures: a screening questionnaire to assess the likelihood of personality disorder, an assessment of social functioning and a measure of service utilisation during the previous six months.

d. Delphi study

We designed a 54-item Delphi questionnaire based on data collected during the first phase of the study and feedback from users, providers and commissioners of services. Delphi propositions focused on the organisation and delivery of dedicated PD services, staffing issues, user involvement and peer support, priorities for service development and outcome measures. The Delphi panel comprised 99 people with approximately equal numbers of users, providers, and expert authors who had published at least one paper on community services for people with PD in Britain during the previous 10 years. Three waves of questionnaire were sent out together with feedback on individual and group responses from previous rounds.

Findings

a. Organisational evaluation

The 11 pilot services provide a diverse range of innovative approaches to helping people with PD and serve areas ranging from metropolitan boroughs to county districts covering over two million people. Services received between £280,000 and £1 million per annum. Despite these differences there was broad agreement about the basic parameters for providing services to people with PD. They should:

- be delivered over a relatively long period of time

- validate rather than dismiss users' experiences

- work flexibly with service users while ensuring the service they provide is consistent and reliable

- promote autonomy and choice

- deliver more than one intervention of varying intensity to suit those with different levels of motivation

- facilitate access to peer support and group work

- help service users generate short and long-term goals

- help service users plan how they will deal with crises

- ensure that service users are given time to prepare for leaving the service

- deliver social as well as psychological interventions

- combine direct service provision with support for colleagues working in other settings aimed at increasing their capacity to work with people with PD and decrease social exclusion

- ensure staff work closely together and receive regular supervision.

Staff working in general health and social care told us that pilot services were valuable because general services lacked the time and skills needed to help people with PD. Some felt that existing services were often unhelpful and that the development of dedicated services challenged the notion that there was nothing that could be done to help people with PD. Others were disappointed that dedicated services were unwilling to work with people who were very chaotic or not sufficiently psychologically minded. Staff who had received training and support on the management of people with PD generally welcomed this. Most of the commissioners we interviewed had been involved in setting up pilot services and were positive about them. However, they expressed concerns about the small number of service users that some had taken on and were keen that others expand the geographical area that they served. Commissioners felt that PD services should become more integrated with other services. Others warned that services for people with PD were not a high priority and that unless it could be demonstrated that they resulted in savings elsewhere, long-term funding was uncertain.

b. User-led qualitative study

- Service users often came into dedicated PD services with painful experiences, both in their own lives and in relation to previous contact with services. Many talked of feeling rejected and dismissed by mental health services.

- Service users approached PD services with a sense of hope combined with fears of rejection from what many had been told was their 'last chance'.

- Some service users reported that the assessment process was distressing and that they were not sufficiently supported during this time.

- Service users appreciated flexibility and choice and the easy accessibility of both services and staff.

- Services that offered a range of options for therapy, peer support and extra help at times of crisis were highly appreciated.

- Members of staff at pilot services were valued for their sincerity, non-judgemental approach, for being caring, supportive and knowledgeable, and for treating service users with respect.

- Many service users spoke of the value of peer support, of sharing problems and coping strategies with other people, and of the power of learning from and helping others. There were difficulties, too, in peer relationships. In some services, people encountered cliques or felt burdened by other people's problems.

- The extent to which rules were explained and negotiable was an important issue: in some, service users were able to appreciate and feel some ownership of the rules as a result of contributing to their formulation. Equally, it was important that rules be interpreted and applied consistently.

- Group process and group therapy gave rise to both critical and appreciative comments. In some instances, service users felt that the way in which group therapy operated was not properly explained and felt mysterious. Others were appreciative of what they learned in groups, and of the peer support they gained there. Nevertheless, there was an appeal for individual therapy in services where this was not an option.

- Most service users spoke of positive changes resulting from their contact with the pilots, including: the way they felt about themselves, their behaviour, and in the ways they related to others. Negative or insignificant outcomes were mentioned by only a few. Service users expressed concerns about what would happen to them when their time in contact with the service came to an end.

- Few services had begun to provide systematic support for carers and family members at the time of this study. In the few services where they had, carers greatly appreciated both the information and advice they were given and the chance to meet and talk with other carers.

c. Cohort study

We obtained basic demographic data on 1428 people referred to the 11 services over a 34 month period. Mean age of those referred was 35.2 years (SD=9.3), 500 (35.1%) were male, 90 (7.8%) non-white, and 1017 (94.4%) had had previous contact with mental health services. Most referrals were made by secondary care services, with the exception of those where self-referral was either encouraged or required. Main reasons for referral were mental distress, social problems, self-harm and suicidal behaviour. Between 31% and 100% of those referred were taken on by the service. The main reason why people were not taken on was because they either did not attend or complete an assessment. Men were less likely to engage with services than women.

Detailed clinical data were obtained on 457 people at 10 of the 11 services. Levels of personality disturbance were high across all 10, with between 92% and 100% meeting criteria for probable personality disorder. Levels of social dysfunction were also high, and greater than those reported in a previous study examining people presenting to emergency medical settings with acute mental health problems. There were also high levels of utilisation of other services with 47% reporting having attended an Emergency Department, 37% being admitted to hospital and 7% having been charged with an offence during the previous six months.

335 (44.4%) of 755 users who started to use a service were no longer in contact with it. Approximately a third had completed an intervention, with the remainder dropping out of contact with the service or leaving prematurely for other reasons. BME service users and men were less likely to remain in contact or complete an intervention. Those with higher levels of inter-personal problems were more likely to drop out of contact with services and there was a trend towards people who referred themselves to services being more likely to remain in contact or complete an intervention.

d. Delphi study

Consensus was reached on only 21 (39%) of Delphi items. These included the need for dedicated services and the belief that interventions should be delivered over years rather than months. Delphi respondents highlighted the importance of personal qualities of staff working in PD services, the value of teams which included people with different professional and non-professional backgrounds, and the need to provide staff with a regular forum to reflect on their practice. There was a marked lack of consensus around issues such as the role of home-based assessment, assertive outreach, medication, in-house crisis support, and whether all people with PD should have access to user-led services.

Delphi participants rated outpatient psychological services, day treatment programmes and consultation services as priorities for service development and stated that all services needed to work to reduce stigma and discrimination experienced by people with PD. Services should be judged by their ability to improve quality of life and social functioning of people and decrease levels of mental distress.

Conclusions

This study coincided with the first two years of the operation of most of the pilot services. While this allowed us to track some of the challenges they faced, services were in transition and it is possible that some of the problems that we identified were resolved in the period after data collection stopped.

The 11 pilot services delivered a broad range of interventions for people with PD over a short period of time. Pilots succeeded in engaging and retaining many people in services, although half of those referred were not taken on for direct service provision.

Despite major differences in the organisation and content of interventions delivered by the pilots, there was widespread agreement about key aspects of how such services should be delivered. Services need to deliver psychological and social interventions, provide opportunities for peer support and help people access leisure activities, training and employment. They should provide long-term interventions, take on responsibility for coordinating care and consider accepting self-referrals. Teams providing dedicated PD services need to have regular supervision, preferably with an external supervisor.

Given the high prevalence of PD, services face the challenge of how best to use their limited resources. Dedicated services may be able to increase their capacity by developing structures that facilitate peer support. The unwillingness of many to engage with dedicated services as they are currently configured mean that most people with PD will continue to be treated by generic services. Support for those working in these services will therefore continue to be an essential component of the work of dedicated PD teams.

Referrers, commissioners and service users stated that general mental health services had often not served people with PD well in the past. Service users told us that contact with the pilots had helped them change the way they felt about themselves and related to others and challenged the notion that there was nothing that could be done for people with PD. Service commissioners told us that services for people with PD were not a national priority and highlighted the need for research and audit to examine whether dedicated services resulted in direct cost savings.

Expert authors, service users and providers believe that outpatient services delivering psychological treatments, dedicated day services and consultation services are the priorities for service development, but consensus is lacking about important aspects of service delivery such as the role of outreach services and the use of medication.

The 11 pilot services achieved a considerable amount over a limited period of time and they appear to be delivering high-quality care to a group of people who have been poorly served in the past. We believe that the lessons they learned during the first phase of their development and feedback from service users can guide the development of new services for people with PD. Dedicated PD services need to continue to monitor the impact of their work on the extent to which other services are used. Further attention also needs to be given to the impact of assessment procedures and the needs of men with PD and BME service users.

Disclaimer

Please note: The views expressed in this report are those of the research team and are not necessarily shared by those of the Department of Health or the funder (National Coordinating Centre for NHS Service Delivery and Organisation).

1 Background

Personality disorders (PD) are a heterogeneous group of conditions in which there are pervasive and inflexible patterns of inner experience and behaviour that deviate markedly from cultural expectations (American Psychiatric Association, 1994). High levels of mental distress and impaired social functioning mean that these disorders have a significant impact on the lives of the person affected, their families and carers and society as a whole. It is estimated that between 3% and 7% of people in Britain have a personality disorder (Coid *et al*. 2006). Most forms of PD are more prevalent among men than among women, and in inner-city areas compared to suburban and rural ones. Emotional and inter-personal problems associated with PD mean that the prevalence of personality disorder is generally higher in healthcare settings than in the general population. Approximately 40% of people in contact with substance misuse and mental health services have a PD (de Girolamo & Dotto, 2000; Bowden-Jones *et al*. 2004). Levels of PD are also higher among people in contact with criminal justice services, with as many as 80% of people in prison having PD (Singleton *et al*. 1998).

1.1 Current service provision

The evidence base for the effectiveness of interventions for people with PD is limited. Most research that has been conducted has focused on Borderline PD. However, small numbers of randomised trials with small sample sizes mean that, even in relation to this disorder, there is considerable uncertainty about the value of specific interventions (Binks *et al*. 2006; Brazier *et al*. 2006). It seems likely that psychological treatments can help to reduce mental distress and self-harming behaviour, and that selective use of psychotropic medication can also help to alleviate symptoms experienced by people with Borderline PD (Leichsenring & Leibing, 2003; Binks *et al*. 2007), but the generalisability of these findings to other forms of PD is unclear.

There is even less evidence on which to base recommendations about the organisation and delivery of services for people with PD. Observational studies suggest that therapeutic communities help people with PD who have complex needs (Chiesa *et al*. 2002) and experimental research has demonstrated that psychodynamically informed psychotherapy delivered in the context of a specialist day hospital reduces the level of inpatient treatment that people subsequently use (Bateman & Fonagy, 1999).

A survey of Mental Health Trusts in England in 2002 (National Institute for Mental Health, 2003b) reported that 17% provide a dedicated personality disorder service, 40% provide some level of service and 28% provide no identified service. The remainder did not respond. General principles, based on expert opinion, have outlined the approach that should be taken to managing people with PD (Holmes 1999; Sampson *et al*. 2006). It has been argued that, in England, people with PD should have access to specialist Outpatient Services with specialist PD Day Unit in areas of high morbidity and Regional Residential Units to meet the needs of those with very severe problems (Fahy, 2002).

In January 2003, the National Institute for Mental Health (England) published its policy implementation guidance on services for people with personality disorder: Personality Disorder: No longer a diagnosis of exclusion (National Institute for Mental Health, 2003b). This built on the National Service Framework for Mental Health's standards four and five (Department of Health, 1999) on effective services for people with severe mental illness. It outlines good practice for developing services in general adult-community mental health settings and forensic settings. This was followed by the publication of recommendations on the design and commissioning of education and training on PD (National Institute for Mental Health, 2003a).

While services for people with PD were not included in the original National Service Framework for Mental Health, Special Health Authorities have been required to report on services for people with PD during the last two annual reviews.

1.2 Service user views

Previous studies have examined the views of people with PD and shown many feel stigmatised by this diagnosis and dissatisfied with existing services. People with PD have described being told they would not be treated, being called 'attention-seeking' and labelled 'bed-wasters' (Haigh, 2002). In a survey of 50 service users in Essex, less than half said they had been helped by mental health services and 80% believed their care had deteriorated as a result of their being given a diagnosis of PD (Ramon *et al*. 2001). Haigh (2002) found that service users would like to experience services that are reliable, help them to develop personal skills and foster openness and trust. Service users also reported they wanted more choice, the ability to refer themselves to services and direct access to 24-hour crisis care.

1.3 National service developments

In 2004, the Department of Health and the Home Office commissioned NIMHE to deliver a National Workforce and Training Programme. This aimed to improve access to treatment by investing in workforce capabilities and continuing professional development. In 2005 local commissioners and stakeholders developed Capacity Plans for personality disorder services. These aimed to facilitate and support development of appropriate services locally and regionally by: mapping current services; highlighting need and demand in services; defining pathways through services; identifying capacity of current services and outlining development targets for meeting this capacity.

To supplement these initiatives the Department of Health commissioned a range of new services for people with PD: five largely residential specialist forensic services and 11 community-based 'pilot' services. The community-based services were asked to develop innovative interventions that promote personal recovery and social inclusion for people with PD. The aim was to commission a variety of pilot services that reflect a wide range of approaches to helping people with personality related problems. It is the 11 pilot services that are the subject of this study; the specialist forensic services are the subject of a separate research project.

1.4 Lessons learned

Although evidence about the effectiveness of specific treatments for people with PD is increasing, relatively little is known about how services to deliver these are best organised. The establishment of these 11 pilot services provided an excellent opportunity to learn lessons about organisational, therapeutic and other factors that result in high-quality care. Through comparing different services and their outcomes we set out to generate knowledge that can help inform the development of future services for people with PD.

1.5 Study aims

The study aimed to evaluate pilot community services for people with personality disorders, and to use findings to make recommendations for future service development.

In order to achieve these aims we set out to:
- describe the organisational form, activity and function of pilot services and compare these with national guidelines for the management of people with PD
- compare aims and objectives of services with those they actually deliver
- measure changes in service health and social outcomes, service utilisation and direct costs of a cohort of patients using these services

- identify organisational, therapeutic and other factors that service users and providers believe result in high quality care for people with personality disorders.

In our original study proposal we also set out plans to measure changes in service utilisation, clinical and social outcomes, and the direct costs of care among a cohort of people using the pilot services. However, we were unable to devise a system for obtaining informed consent to collect follow up data (see section 2.6.2) and were unable to fulfil this study aim.

2 Study methods

2.1 Overview

In deciding the optimum design of this study we needed to take account of several important methodological and logistical considerations. From a methodological perspective, we needed to combine qualitative and quantitative approaches in order to capture the complexity of the services and the outcomes they sought to achieve. Logistical issues included the diversity of the pilot services and their geographical spread over the length and breadth of England, from Cumbria in the north-west, to Essex in the east and Plymouth in the south-west. Because all the pilot services had been required to develop methods for locally evaluating their services, we needed to ensure that the methods we used minimised inconvenience to providers and users and did not disrupt service provision. Having been asked to use the data we collected to make recommendations for service provision, and in anticipation that views about the development of PD services would be mixed, we decided to include a formal consensus-building exercise in order to capture the expertise of a wide variety of different stakeholders and see if it would be possible to build a consensus around key aspects of the organisation and delivery of services.

In consultation with the Department for Health, and service leads of the 11 pilots, we therefore agreed to focus on collecting qualitative data from users, providers and commissioners of the services. We set up a method for quantifying levels of service activity and exploring the demographic and clinical characteristics of a sample of all those referred to the services in a way which would facilitate cross-comparison between the different services. In addition to holding regular project management meetings we set up a Project Advisory Group to which representatives of each of the 11 pilot services were invited, together with service users who were involved in commissioning the pilots' and other 'experts through experience'.

The final study design comprised four interlinking components:

- an organisational evaluation of the context, form, function and impact of all eleven PD pilot services

- a user-led qualitative evaluation of service quality from the perspective of service users

- a cohort study examining the demographic and clinical characteristics of a sample of people who are referred to and use these services and

- a Delphi study examining the level of consensus there is among academics, service users and providers about lessons that can be learned from the study and recommendations for future service developments.

2.2 Study setting

The 11 pilot projects provide the setting for this study. Details of the location and a summary of services provided by each of these pilots are provided in Table 3.2.

2.3 Project Advisory Group

Members of the Project Advisory Group (PAG) are listed at the beginning of this report. The PAG met on four occasions during the course of the study and played an important role in helping us finalise topic guides for use in the organisational evaluation and user-led qualitative study. The group also played a role in deciding the content of the 'minimum data set' for use in the cohort study and suggested items for inclusion in the Delphi questionnaire. At a meeting of the group in March 2007, draft findings from the study were presented and feedback from members was used in drafting the final project report.

2.4 Organisational evaluation

The aim of the organisational evaluation was to examine the formal and informal structure and care pathways of each of the 11 pilot services. Through collecting longitudinal data on services we set out to examine changes in structure and staffing and compare aims and objectives of services at baseline with those they actually delivered. We aimed to investigate the sustainability of services and the effect they have on other local services, including any change in attitudes towards PD. This component of the study involved an examination of service-level agreements and other written information and collection and analysis of qualitative data from in-depth interviews with service commissioners, referrers and staff at each of the 11 pilot services.

2.4.1 Data collection

A senior researcher with previous experience of conducting organisational studies (DR) began by examining available policy documents, and arranged early visits to interview the clinical leads of each service. Subsequent interviews were arranged by asking service administrators or managers to put out a call for volunteers, with the suggestion that DR would visit on at least two days to permit a range of staff with different backgrounds and commitments to take part. We selected potential referrers for interview from suggestions made by service leads. We asked service leads to nominate a number of potential referrers, including those who had many and few referrals. We used these contacts to generate further suggestions for potential interviewees. For those pilots that provided more than one intervention we tried to speak to a least two for each component of the service. Commissioners for each of the pilot services were also interviewed – one for each of the commissioning bodies responsible for purchasing services in the area(s) served by each of the pilots.

Semi-structured topic guides were drawn up on the basis of the literature on PD, in consultation with the research team, to stimulate reflection and prompt exploration of some of the themes that were likely to be important to all stakeholders. The organisational aims of the study led us to consider the model of therapy, patient pathways, developmental and staffing issues, crisis management, risk management and governance, relations with other providers and user involvement as important. Topic guides were reviewed and revised frequently throughout the study, as interviewees raised issues that were important to them. Midway through the project, topic guides for use with providers, commissioners and referrers were shared with members of the Project Advisory Group (PAG), which allowed us to consult both providers and users of services, and to promote any areas of discourse that we had inadvertently neglected.

The key challenge in this aspect of the study was to manage the enormous wealth of data collected in the interviews, and to limit the interview length to what seemed reasonable. This was achieved by carrying out constant and incremental review of the data collected from each pilot, in order to identify gaps in understanding of the model that could be addressed in subsequent interviews with staff from the same site. Those issues and practices, e.g. reflection on leadership and supervision, functions of staff within user-led groups, which generated a range of contemplative responses were worked into most interviews with staff, time permitting; those which appeared less controversial and more factual, e.g. how referrals were handled, were eliminated once two or more matching responses from the same service were recorded. All interview files were stored in pilot-specific computer folders.

In all cases bar one, the Icebreak service in Plymouth, the data were collected on at least two visits in order to track the development of services, with three visits being the median. All interviews with service providers were digitally recorded with signed consent of respondent and transcribed for the purpose of detailed analysis. Interviews with referrers and commissioners were conducted by telephone. In each instance verbal informed consent was obtained to make a digital recording of the interview.

2.4.2 Data analysis

Transcripts and interview summaries were subject to thematic hand analysis. The researcher (DR, who also carried out the provider interviews) achieved immersion in the data by reading transcripts of all interviews as they were generated. Analytic induction was employed to build an initial framework from the first round of interviews: emerging themes were identified and incorporated into subsequent interviews. The initial coding framework was based on the aims of the organisational study, and therefore linked into the topic guides. A reflective approach was taken, continuously reviewing and refining both the topic guide and the coding framework to ensure that (a) gaps in the data were taken into subsequent interviews and (b) all areas that respondents had spoken about had been covered by the framework.

The transcript data was largely analysed as it was generated, in order to amend topic guides to fill gaps in the data. The initial framework for the case studies was drawn up from early interviews at the first two sites, extended to take in the further information which came from reviewing the interviews, and then reduced, in consultation with the Project Management Group, to a common structure to fulfil the need for brevity of reporting. A thematic framework grounded in the data therefore emerged and grew during the course of the study. Every single interview was extensively reviewed on-line, in batches focusing upon the individual pilot service. Each interviewee was given a unique coding. Extracts of the interviews – sourced to the speaker – were cut and pasted into (a) the coding framework for the case study and (b) the coding framework for Section 4. The framework headings were added to and, less often, amalgamated. Triangulation of data sources from different staff members was important to justifying inclusion and, toward the end of the study, the qualitative researchers were able to interrogate and make comparisons with quantitative data on each service to check some of the more factual statements made in interviews.

Early on in the project, it became clear that two types of data were emerging from the organisational study: data specific and important to the individual model *and* common themes in the data that could inform an underpinning service philosophy and model for a variety of services for people with PD. It was therefore decided that the same interviews should be analysed to reflect these two parts. This also permitted us to report on material, especially about difficulties, which providers kindly shared for the greater good, but which they might have been reluctant to see identified directly with their services. None of the difficulties reported was peculiar to individual pilots, which is highly suggestive that they are predictable and the account can therefore help others to plan for them. Confidentiality was important to the reporting of this project. The final case studies were shared with the service leads in order to reduce inaccuracies and introduce recent changes.

Given the amount of data collected and the limits of staffing, it was not possible to conduct independent analysis by a second researcher, although a second researcher (KP) exclusively and independently carried out and analysed the interviews with referrers and commissioners.

2.5 User-led qualitative evaluation

This service-user-led module of the study employed qualitative research methods to evaluate the pilot services from the perspective of their current and past service users and carers. The aims of this component of the study were to explore individuals' experiences of the services with a view to identifying factors which are believed to influence perceptions of service quality and outcomes for service users, and those which affect eligible service users' decisions to engage, or end contact, with services.

2.5.1 Recruitment, training and supervision of service user researchers

A team of 11 Service User Research interviewers was recruited via service user research groups and networks across England during the autumn of 2005. In January 2006, they undertook four days of intensive training delivered by a Mental Health Foundation-based research team. The training provided information about the background to the project, as well as detailed information on qualitative research methods, including managing bias, recruitment and sampling strategies, interviewing skills, use of the interview schedule, ethical issues and plans for supporting and supervising user researchers, in order to ensure consistency of approach across the different pilot sites. Telephone and face-to-face peer support and research supervision were provided throughout the period of data collection by senior members of the Mental Health Foundation research team. Services also ensured that a familiar member of staff was available to provide support and debriefing for service user / carer participants at the time of or directly after the interview in case they felt the need for support.

2.5.2 Sampling and recruitment strategies

A purposive sampling strategy was employed in order to achieve the aims set out above.

The primary sampling frame sought seven to ten current service users and up to three carers and past service users at each site for individual interviews, plus a further six current service users for at least one focus group interview where this was appropriate to the model of service provision at that site. Within these categories a secondary list of sampling criteria was employed to seek a mix of gender, ages, component of service used and length of contact with the service which was broadly conversant with the mix of service users in contact with each service. Service users who were currently in the process of engaging with the site or ceasing contact with the site and for whom taking part in the research might disrupt their formation or maintenance therapeutic relationships, and service users for whom interview participation might be considered potentially distressing at that point by the staff responsible for their care and support were not asked to participate in the study.

In order to assist with determining the application of this sampling and recruitment strategy to each site a researcher visited each site and met with a named staff member. Within the overall strategy, sampling and recruitment was tailored to the service model, level of service user involvement and client group at each site. In most cases information about the research was disseminated via staff, site-based service user groups using accessible information sheets and flyers that gave service users the opportunity to put themselves forward as possible interviewees. Where possible, past service users were identified and contacted by staff at the sites and asked for their consent to be contacted by the research team. Carers were identified where possible by service user participants and only interviewed with service users' consent.

2.5.3 Interview schedules and topic guides

Interview schedules for interviews and focus groups with service users and carers were developed on the basis of a review of service users' and carers' views and experiences of personality disorders services as represented in published research and feedback from members of the Project Advisory Group. They consisted of a series of open-ended questions covering the following themes: information received, deciding to try the service, the process of coming in, assessments and diagnosis, support received, contact and relationship with staff, relationships with other service users, service user involvement, outcomes and ideas for improvements.

2.5.4 Data collection methods

Each site responded differently in the ways that they were able to assist the research team on appropriate access to participants, sampling and recruitment. For this reason the numbers of current service users, carers and past service users accessed at each site varied quite widely. Specific examples included a site that was working with a local research team which had asked participants in the local evaluation to sign an assurance that they wouldn't participate in any further research, sites that freely contacted past service users – even those with very negative perceptions of the service – in order to give them a voice in the research, and sites in which access to past service users was impossible.

From March to June 2006 pairs of service user researchers, and in one instance a member of the MHF-based research team, visited each service site in order to recruit and interview research participants via one-to-one interviews and focus groups, as appropriate to the sites and participants. The great majority of qualitative data were tape-recorded and transcribed verbatim. Where participants did not consent to their interviews being tape-recorded, researchers took comprehensive field notes by hand, using verbatim language where possible, which were checked back with participants for accuracy at interview.

2.5.6 Data analysis and validation

All taped interview and focus group data were transcribed. Seven of the service user researchers were trained alongside Mental Health Foundation-based research team members in Richie and Spencer's Framework approach to qualitative analysis (Ritchie & Spencer, 1993). An initial analytical framework was developed based on items in the interview schedule. This was then applied consistently to the data from each site, allowing researchers to identify emergent themes for inclusion in the framework and feedback to the central validation team at the Mental Health Foundation via regular validation supervision meetings during the analytical process. Qualitative data were analysed and findings validated by one of the researchers who had been present at the interviews.

From this in-depth analysis of verbatim transcripts, site summaries were produced detailing issues arising from service users' journeys from first contact with sites through to outcomes. Learning points were extracted from these summaries and these are presented in Section 3, full summaries, for all but one site, are presented in Appendix A. At this site, the Leeds Personality Network, the number of interviews conducted was too small to assure anonymity of the respondents. The findings from this site are included along with others in Section 4.

This analytical process was supervised and validated via group and individual meetings with members of the validation team comprising Mental Health Foundation lead researchers (SLG, AF & IR). Validation focused on credibility and auditability as the analytical processes of each researcher were trailed from raw data, through coding, charting and summarisation stages. Through this process the initial thematic framework was augmented with emergent themes from analyses across sites, which were then formed into an over-arching framework to describe the study findings across the whole national data set as presented in Section 4.3.

2.6 Cohort study

At the start of the study the principal investigator (MC) contacted service leads at each of the pilot services and obtained information about methods they were using to collect data from their service users. It quickly became apparent that services were at different stages of development; some had already started providing services and others were still in the planning stages of their development. Some services had implemented plans for local evaluation and others had not. It was also clear that those services that had either agreed plans for collecting data, or were already collecting it, were collecting a wide range of different variables with very little data in common across the services.

At the first meeting of the Project Advisory Group, we reached agreement with representatives of the pilot services that they would endeavour to use two data sheets designed specifically for the study which would provide a consistent method for recording data and facilitate comparison across the study sites. We asked pilot services to complete a 'Care Pathway Record form' for all those referred to their service and a 'Minimum Data Set' on all those taken on by the service. We also made suggestions for questionnaires that could be used to measure other key variables across the 11 services and agreed arrangements for obtaining written informed consent from service users that would enable researchers from the National evaluation team to obtain follow-up data one year after the collection of baseline data.

2.6.1 Study questionnaires

A. Care pathway record

A two-page datasheet that we asked service providers to complete for a consecutive sample of all people referred to their service. The sheet was designed to provide a means of comparing demographic characteristics and details of the assessment process and services provided across each of the 11 pilots.

B. Minimum dataset

This single sheet of paper comprised four items:

- The Standardised Assessment of Personality – Abbreviated Scale (Moran *et al*. 2003). An eight-item screening questionnaire which provides a valid measure of the likely presence of Personality Disorder.

- A single-item question exploring motivation to change (Tyrer *et al*. 2003a).

- The Social Functioning Questionnaire (Tyrer *et al*. 2005a). A 12-item measure of social functioning that has been used in previous evaluations of interventions for people with personality disorder.

- Seven questions on service utilisation, which were specifically developed for the study.

C. Additional baseline data

- Mental Health Inventory. A five-item measure of general mental health (Berwick *et al*. 1991).

- Current use of alcohol or illicit drugs.

- The Helping Alliances Questionnaire. A four-item patient-rated measure of quality of care (Priebe & Gruyters, 1993).

- The four-item Patient Satisfaction Questionnaire (Shipley *et al*. 2000).

2.6.2 Data collection methods and follow-up

The original plan was that staff in pilot services would obtain written informed consent from service users and collect baseline quantitative data. Contact details would then be passed on to researchers from the study team who would collect follow-up data 12 months later. However, it did not prove possible to implement this plan because services were unhappy about asking service users to provide written informed consent to participate in the study. Service providers told us that asking users to provide informed consent may interfere with the process of engaging users who may already be ambivalent about seeking help. In a minority of instances, procedures for obtaining informed consent to participate in a local evaluation project precluded involvement in the national evaluation. Three of the 11 pilot services agreed to approach new service users and ask them to provide written informed consent to be followed up as part of the study. However, only a small minority of service users at each site agreed to participate.

We therefore devised an alternative strategy which involved pilot services agreeing to incorporate items from the minimum dataset into their routine assessment and our obtaining ethical committee approval to obtain copies of clinical and demographic data on people referred to each of the services.

We attempted to collect data on all those referred to services for at least six months after their inception. When examining the outcome of referrals we used a cut-off point of 30 April 2006 in order to ensure that follow-up data were available over a period of at least six months, i.e. until November 2006.

2.6.3 Sample size

We based the sample size on previous studies that have demonstrated large reductions in service utilisation among people with borderline personality disorder who receive structured psychosocial interventions. For instance a sample of 24 patients would be needed to have 80% power and 5% level of statistical significance to demonstrate a reduction in the mean number of inpatient days from 17 days to 8 days (SD=11) that were found between day patients and control patients in the first 12 months of the evaluation of a day hospital-based treatment by Bateman & Fonagy (Bateman & Fonagy, 2001). Anticipating that many people referred to pilot services would not engage with them, and that many who were offered services would not accept them, we set out to collect data on 100 consecutive referrals at each of the 11 pilot services.

2.6.4 Data analysis

All data were entered onto SPSS (Version 14.0) for data analysis. Distribution and central tendency (such as Standard Deviations (SD) for normally distributed continuous data) were examined and simple descriptive statistics used to examine differences in characteristics of those referred to and taken on by services. In exploring the proportion of people who were referred to services and who engaged with them we have excluded all referrals made after April 2006, because some of these had not been fully processed by the end of the period of data collection. We also excluded those referred to two services: one where the population was young and people had personality disturbance rather than disorder, and the other which provided a case consultation service rather than delivered direct services to users. Univariate and multivariate tests were used to compare the characteristics of those referred to services by health and social care professionals and those who self-referred. Finally, we examined characteristics associated with early drop-out from services, using binary logistic regression.

2.7 Delphi study

This component of the study was designed to examine the degree of consensus among service providers, service users and researchers regarding the form and content of specialist services for people with PD. Delphi studies involve obtaining views of experts and using controlled feedback on individual and group responses in order to stimulate reflection and consensus (Murphy *et al*. 1998).

2.7.1 Development of the Delphi questionnaire

Items for inclusion in the Delphi questionnaire were derived from the first round of data collection from the organisational evaluation and the user-led qualitative component of the study. A series of propositions based on views of service users and providers about the focus, form and organisation of specialist services for people with PD were drawn up, to which we added further items suggested by members of the project management group and Project Advisory Group. The items were then reviewed by the research team including service user researchers. The first round of the Delphi survey consisted of 49 statements categorised into: organisation of services (13 items); service delivery (19 items); staffing issues (9 items); service user involvement and peer support (8 items), and two ranking items on service development (11 items) and service outcomes (7 items).

Each proposition was accompanied by a nine-point rating scale ranging from one (disagree strongly), through to five (neither agree nor disagree) to nine (agree strongly). For the ranking questions on priorities for service development the scale was marked from 'should not be provided' to 'highest priority'. For the ranking questions on outcomes that should be used by services for people with PD the scale was marked as 'unimportant' to 'most important'. All participants were asked to state their background and main therapeutic approach at the start of the exercise. A copy of the full first-round Delphi questionnaire can be found in Appendix C.

Space was provided in the first-round questionnaire asking participants to suggest additional items in round two. Eight additional suggestions were made which were collated into five additional items which were included in the round-two questionnaire, i.e. responses were obtained on 54 items (plus two ranking items) during the course of the Delphi exercise.

2.7.2 Selecting members of the Delphi panel

We attempted to identify equal numbers of service providers, service users and expert authors for the Delphi panel. We approached service leads at each of the 11 pilots and asked them to nominate three people who had had a central role in developing and delivering the service. We used contacts with the Department of Health, researchers from the Mental Health Foundation and the voluntary organisation Borderline UK to identify an equal number of service users who had either used or advised on the development of services for people with PD. Finally, we used contacts of the project management group and an electronic search of bibliographic databases to identify expert authors who had published at least one peer-reviewed paper on the organisation and delivery of community services for people with PD in Britain during the previous 10 years. Invitation letters were sent to academic experts as defined above and, from this, 31 were recruited. With 33 service providers and 34 expert service users, there were 99 members of the Delphi panel in total. Service user participants were offered a £40 postal order as an honorarium after completion of the third-round questionnaire.

2.7.3 Data collection and analysis

Surveys were mailed out to all participants by e-mail unless the participant requested a hard copy. Two reminders were sent to those who had not responded. Surveys were coded, and participants were not asked to identify themselves on the questionnaire.

Results were entered into SPSS and Excel and the median and interquartile range calculated. For analysis of consensus, the nine-point scales were divided into 1–3 'disagree', 4–6 'neutral' and 7–9 'agree'. The percentage of participants from all groups falling into each of the bands was calculated. Where 75% or more of participants were in the same band for each item, this was said to have reached consensus. Calculations of median, interquartile range and consensus were also made by participant group, i.e. service users, service providers and academic experts. Items on priorities for service development and outcomes were ranked by median, then mean.

For the second round, those items with consensus above 75% were excluded. The ranking items were also removed. Next to each item a box was included, indicating the individual participant's response to the first round, the median response (described as the 'group response') and the interquartile range (described as the 'consensus level'). Where there were notable differences in responses between participant groups, variance greater than or equal to two, a statement was added indicating this. This feedback was designed to give participants as much information as possible about the responses of the group.

For round three, consensus levels were calculated as in round two. Again, individual and group responses as well as interquartile range were indicated, together with new statements about group difference. Feedback was given to participants on those items on which consensus had been reached over rounds one and two, together with results on priorities for service development. In addition, several of the items were reworded slightly as some participants had indicated that the statements were ambiguous or unclear. It was hoped that this would better enable consensus to be developed.

2.8 Ethics

Ethical committee approval was obtained via the Central Office for Research Ethics Committees prior to the start of data collection. Early on in the study it became apparent that most of the pilot services were happy to use the minimum dataset and Care Pathway record form to collect demographic and clinical data, but were not prepared to obtain written informed consent from their service users (see section 2.6.2). We therefore wrote to the reviewing Ethics Committee and asked for amendment to the original application. This provided approval for researchers from the national evaluation team to receive de-identified copies of data sheets from the pilot services without written informed consent from users, provided that – as was planned – the researchers had no means of identifying the subjects.

Potential participants in the user-led qualitative study were identified by service providers and asked to provide verbal consent to be approached by a member of the National Evaluation Team. Each participant was provided with an information sheet, which stated the purpose of the study, the need for their involvement, what their participation would entail, issues surrounding ethics and confidentiality and a contact number for the study team. Participants were also given an opportunity to discuss any queries about the research with the service user researchers. Written informed consent was gained from all participants and all were debriefed and thanked for their participation at the end of the interview / focus group. Data were handled and analysed according to good ethical practice, using anonymised participant codes at all times.

All data from the study were stored in accordance with the requirements of the Data Protection Act, with electronic files password protected and held on a secure server and hard copy files stored in locked filing cabinets.

3 Case studies

Findings from the organisational evaluation and the user-led qualitative study of service quality from the perspective of service users are presented in the following two sections of the report. In this section we provide a brief summary of the aims, organisational form and function of each of the 11 pilot services in tabular form. This section is accompanied by detailed case studies of each of the pilot services which can be found in Appendix A. Rather than reduce their length and remove information that may be of interest to those wanting to obtain a detailed account of service models, we decided to place them in a separate appendix. The following section is therefore limited to a short summary of the case studies in tabular form. Those wanting to obtain a proper picture of the services provided by each of the pilots are referred to Appendix A.

In Section 4 we present overarching themes based on interviews with service users, providers, referrers and commissioners. Learning points from service providers are based on comments received by the research team at the start of 2007, except those from the Leeds Personality Disorder Network, which are based on discussions at a Learning Forum organised by the Department of Health and held in November 2006, which was attended by members of the research team.

3.1 Data collection

Details of the number of interviews and focus groups we conducted at each service are presented in Table 1. We interviewed a total of 89 service providers, 26 referrers and 13 commissioners. Data were collected from 108 current service users via individual interviews and / or focus groups. Individual interviews were also conducted with 10 carers and 15 ex-users who had either completed their treatment or dropped out of contact with the service. Seventy per cent of service users who were interviewed were female. Ages ranged from 18 to 69 (median, 37.2 years). Ninety interviewees provided data on ethnicity, of whom 64 (71%) were British white, 16 (18%) were white other, and 10 (11%) were from BME communities.

3.2 Summary of service provision

Details of the lead organisation responsible for overseeing each of the pilot services, together with a brief description of the main services they provide, are presented in Table 2. Ten of the 11 services are for adults with PD and personality-related problems. One, the Icebreak service in Plymouth, is for young people aged 16 to 25 who have interpersonal problems and are judged to be 'at risk of social exclusion'. Most of the pilot services deliver a range of tier two and tier three services combined with tier one interventions aimed at supporting the work of colleagues working across a range of other settings. Most services take referrals from a range of different sources but the Service User Network was only open to self-referrals, and the Community Links component of the Camden and Islington Personality Disorder Initiative took all their referrals from primary care. Further details of the aims organisational form and function of the 11 pilot services is provided in Table 3 below. While most of the pilot services consisted of several interlinking components, two of the services (Camden and Islington; Cambridge and Peterborough) provided distinct interventions for different groups of people delivered by separate teams – each of the service components provided by these two pilots is therefore described separately.

Table 1. Details of interviews and focus groups

Name of service	Service providers	Referrers	Commissioners	Users & carers (interviews)	Users (focus groups)
Camden and Islington Personality Disorder Initiative	1 (May 05) 7 (Aug-Oct 05) 3 (June-Aug 06)	5	1	9 [1]	-
Dual diagnosis assessment and response team (DDART)	3 (May 05) 6 (Jan 06)	2	1	6	1 (with 5 service users)
Service user network (SUN)	3 (Mar-May 05) 4 (Jun-Aug 06)	0 Self-referral only	2	10	1 (with 2 service users)
Cambridge & Peterborough Personality Disorder Network	3 (July 05) 8 (June-Aug 06)	2	2	9 [2]	-
The Haven	5 (May 05) 4 (Nov 05)	2	0	12	-
Thames Valley Initiative (TVI)	6 (May-Jul 05) 9 (Jun-Jul 06)	5	3	10	5 (28 service users)
Nottingham Personality Disorder and Development Network	4 (Aug 05) 8 (July-Aug 06)	2	0	10	-
The Olive Tree	3 (June 05) 8 (May 06)	2	1	8	1 (with 8 service users) [3]
North Cumbria Itinerant Therapeutic Community	4 (June 05) 5 (Mar 06)	2	1	10	-
Leeds Personality Disorder Network	9 (June-Sep 05)	2	1	2	-
Icebreak	7 (Aug 05)	2	1	6	-

[1] All from the Umbrella service
[2] All 9 from the Cambridge Complex Cases Service
[3] Focus group comprised 8 people who also participated in individual interviews

Table 2. Guide to key services provided by the 11 pilots

REGION	Lead Organisation/Service	Name of service	Main intervention(s) & target group	Main tiers
London	Camden and Islington Mental Health and Social Care Trust	Camden and Islington Personality Disorder Initiative	Advice, support and training for adults with PD, and healthcare workers	1, 2
	North East London Mental Health Trust	Dual diagnosis assessment and response team (DDART)	Psychological therapies for adults with PD & substance misuse	1, 2, 3
	South West London & St George's Mental Health NHS Trust	Service user network (SUN)	Peer support for adults with PD	2
Eastern	Cambridgeshire and Peterborough Mental Health Partnership Trust	Cambridge & Peterborough Personality Disorder Network	Psychological therapies and consultation service	1, 2, 3
	The Haven Partnership	The Haven	Support, advice, psychological therapies & crisis beds for adults with PD	2, 3
South East	Oxfordshire Mental Healthcare NHS Trust	Thames Valley Initiative (TVI)	Support, advice, and day-TCs for adults with PD	1, 2, 3
East Midlands	Nottinghamshire Healthcare NHS Trust	Nottingham Personality Disorder and Development Network	Support and advice, psychotherapy & day-TC for adults with PD	1, 2, 3
West Midlands	Coventry Primary Care Trust	The Olive Tree	Out-patient individual and group psychotherapy for adults with PD	1, 2, 3
North West	North Cumbria Mental Health and Learning Disabilities NHS Trust	North Cumbria Itinerant Therapeutic Community	Support and advice, internet-based peer support & a day-TC for adults with PD	1, 2, 3
North East	Leeds Mental Health Teaching NHS Trust	Leeds Personality Disorder Network	Care coordination, psychological therapies and advice for adults with PD	1, 2, 3
South West	Youth Enquiry Service/ Plymouth Primary Care Trust	Icebreak	Information & counselling for adolescents with personality disturbance	1, 2, 3

Table 3. Summary of aims organisational form and function of the 11 pilot services

Service	Summary of service aims	Premises and location	Client group, exclusion criteria	Anticipated source of referrals	Staff level and staff training	Interventions delivered	Number of clients and l... of interventions
Camden and Islington: **Skills development service** *Note: this pilot also included a consultation service which is detailed in appendix A*	To improve access to employment adult education and related activities for people with PD	Services delivered through a community-based a voluntary sector agency (Umbrella).	Over 18 years Registered with a local GP Diagnosis of PD (or persistent difficulties in relationships) Exclusion: significant co-morbid mental health problems if not supported by secondary care	Secondary care, primary care with option of self referral	One manager, three skills development workers, and one service user worker. Backgrounds in psychology and arts therapies - all received 3-4 months training in PD	Individual sessions to provide support and advice Personal development groups (e.g. stress management) Groups with a practical focus (e.g. CV writing and interview skills)	Up to 50 service users at any time. Flexible approach to length of intervention - generally between and 12 months
Camden and Islington: **Community links service**	To support the management of people with PD within primary care and tackle social exclusion	Service delivered via 44 local GP practices	Persistent inter-personal difficulties Exclusion: presence of major mental illness or significant involvement of secondary care mental health services	GPs and other primary care workers	Two graduate primary care mental health workers (who joined an existing team of four). Workers received a two-day training in PD and three days on CBT. They were each required to complete a one year post graduate training in primary care mental health	Individual sessions consisting of assessment and supported referral to other services including skills development service or outpatient treatment	All six workers take on a mix of with anxiety and depression a people with PD. People with F offered up to six sessions.

Dual diagnosis assessment and response team (DDART)	To provide a specialist psychological therapies service to people with PD and co-morbid substance misuse To support staff in other health and social care agencies who work with this client group	Premises shared with an existing community team for people with PD within grounds of a community hospital. Access to rooms in community-based clinics	Aged 18 or above Cluster B or C personality disorder Significant substance misuse Some evidence of motivation to change Exclusion: Cluster A PD or antisocial PD (unless accompanied by other personality problems).	Primarily secondary care (including mental health and substance misuse services). The service is also willing to take referrals from primary care, social services and criminal justice system	7.5 full-time-equivalent workers including two managers, an administrator, psychologists, nurses and an occupational therapist.	Services are based on a DBT model, though a range of interventions are provided including comprehensive assessment, case management, motivational enhancement work, and intensive specialist treatments including CBT and DBT.
						Up to 70 service users Length of intervention varies a[ccording to motivation, needs,] progress made by users, but i[s] typically 12 to 24 months
Service user network (SUN)	To develop a Service User Network that provides an inclusive service for people with PD. To support, train and empower key service users themselves to be an integral part of the service.	The service is run from offices located within a mental health unit. Groups are provided in a range of community-based health and social care facilities.	People who believe they have a PD or inter-personal problems that may be helped by contact with the network In order to attend groups prospective users must be willing to complete a crisis plan.	Self referral only. The service was publicised through mental health and social care services.	One senior clinician/ team manager, three personality disorder liaison workers, two part-time service user leads and a part-time consultant psychotherapist.	Service users are offered access to daily 3 hour long facilitated groups during week days, an out of hours peer support service and service user led groups at weekends and evenings (which are not facilitated by staff from the project). Inactive members (who have missed four or more consecutive groups) may be asked to complete an new crisis plan if they want to regain access to the service
						Approximately 80 active mem[bers] at any one time. No time limit is set on length o[f] the service.

| Cambridge & Peterborough: Cambridge complex cases service | To provide access to specialist services for people with personality disorder and a network of services and expertise across agencies. | Attached to psychotherapy service at a general hospital | Adults aged 18 or over who have a personality disorder. There are no absolute exclusion criteria but severe substance misuse, history of violence and lack of motivation to change may mean direct services can not be provided | Primary and secondary care, social services and the criminal justice system. | A full time consultant psychotherapist, full time psychologist, together with a multi-disciplinary team comprising 2.5 FTE psychotherapists, 1 probation officer, 0.8 social worker, 0.6 occupational therapist, 0.5 assistant psychologist and 0.5 administrator | A range of individual and group based interventions including access to a case manager, a psychoeducational group, individual therapy (Including cognitive analytical therapy), group therapy, music therapy and link-working. | Case management is provided to 80 service users at any one[...]. Treatment is generally provide[...] 12 to 18 months after which p[...] can continue to access psychoeducational group and follow-up |
| Cambridge & Peterborough: Peterborough personality disorder service | To provide consultation, support, supervision to those working with PD in health and social care settings | Based at a psychotherapy department in a community hospital | Adults aged 18 or over who have a personality disorder | Mainly primary care and secondary mental health services | One FTE consultant psychologist, 0.5 consultant psychotherapist, 0.8 PD liaison officer, 0.5 assistant psychologist, 0.5 administrator | Three main service components: Consultation clinics for assessment and care planning, individual psychotherapy and general training on PD delivered to health and social care teams | Case consultations are genera[...] delivered over a four to 12 we[...] period. Individual psychothera[...] up to 8 people, is delivered ov[...] month period. |

Service	Aims	Setting	Referral criteria	Referral source	Staffing	Service	Capacity
The Haven	To provide an accepting and safe community that instils a sense of ownership for service users and is accessible 24 hours, 7 days a week.	A large house with garden in a residential area of Colchester.	A current or previous diagnosis of PD. An address within a 25-mile radius of the centre. No formal exclusion criteria but those who present 'unacceptable' risks to others' are excluded.	Predominantly secondary care services and self referral. Though referral is also open to primary care, social services and criminal justice system.	A full-time Chief Executive, a full-time service manager, and a group of full and part-time staff that ensure that there are at least two members of staff present at all times. Most staff do not have professional qualifications but all have relevant experience in health/ social care	Service users have access to a day service offering practical help, support, friendship and a range of informal and formal therapies, an out-of-hours refuge providing up to 5 hours of contact in evenings and weekends, and access to a respite bed for a period of up to 3 weeks at a time.	Up to 100 service users. No time limit: the service aims provide some form of continui contact to the service to all se users
Thames Valley Initiative (TVI)	To develop a *'functionally and geographically tiered service'*, comprising: day treatment, outpatient groups and support for other services across Oxfordshire, Berkshire, and Buckinghamshire.	All three services are sited in community-based facilities. The Berkshire service is at the site of an exiting TC.	Aged 18 or over. Persistent interpersonal difficulties/ PD. Some motivation to change. No formal exclusion criteria but those with psychosis or severe substance misuse may be unsuitable.	Predominantly secondary care services and self referral. Though referral is also open to primary care, social services and criminal justice system.	All three components of the service are made up of a multidisciplinary team of managers, therapists and administrative staff. The Oxfordshire team consists of 12.7 FTE team members, the Berkshire team consists of 5.3 FTE staff and the Buckinghamshire team of 5.8 FTE.	All three services base their interventions on the therapeutic community model. Within this model each service runs outpatient groups, a day-TC programme and a consultation and training services for others working locally with people with PD.	Up to 45 people can use the t day-TC programmes at any7 c People tend to stay for betwee and 24 months, though peopl access outpatient groups ove periods of time.

	Aims	Location	Eligibility	Referral source	Staffing	Service description	Capacity
Nottingham Personality Disorder and Development Network	To support a wide range of agencies in contact with people with PD, to facilitate the development of service-user networks and advocacy, and provide a range of therapeutic interventions.	The service is based at the Mandala Centre – which is situated near the centre of Nottingham. Community-based groups are often sited elsewhere.	Aged 18 or over Meet diagnostic criteria for PD Some motivation to change No formal exclusion criteria but all those who use the service have to give an undertaking to abide by service rules	Predominantly secondary care services, though self referral and referral from primary care, social services and criminal justice system are also possible.	The Network has three staff teams: The Advice & Information service employs four part-time workers, a FTE team leader and a part-time coordinator. The 'Stop & Think' programme has 4.4 FTE staff, headed by a clinical psychologist and the day-TC employs 2 full-time and 3 part-time nurses, a part-time consultant psychiatrist and a consultant psychotherapist.	There are three main components; the Advice & Information service aims to support the work of other services and develop user involvement, the 'Stop & Think' programme provides a weekly outpatient group over a 16-week period and CBT-based group psychotherapy and the day-TC provides a group-based treatment programme .	The 5-day service is made av[...] up to 20 service users for 12-[...] months. The service has the capacity [...] to five Stop and Think groups with up to 8 participants.
The Olive Tree	To provide evidence-based interventions that improve the health and social care of people with PD, and to increase the capacity of staff working with people with PD in other organisations.	The service is provided from community-based mental health premises on the outskirts of Coventry.	A clinical diagnosis of personality disorder. No formal exclusion criteria.	Predominately mental health services, though GPs can also refer directly to the service.	Two full-time team leaders and 10.8 FTE therapists, two skills facilitators and three part-time administrators.	All those taken on by the service are provided with care coordination. A care plan is agreed with the service user which may include individual psychotherapy, structured and unstructured psychotherapy groups and support for referral to occupational activities.	Up to 100 service users. Length of interventions is tailo[red] individual circumstances but i[s] generally around 18 months d[...]

North Cumbria Itinerant Therapeutic Community	To deliver outpatient psychotherapy and day TC programmes for people with PD and to support other agencies working with people with PD.	The service is run from a psychotherapy unit in North Carlisle and runs groups in community-based units.	A clinical diagnosis of PD Recognition of a problem and some desire to explore this No formal exclusion criteria but as people are asked to make an active choice to use the service those involved in legal proceedings are treated under the Mental Health Act would not be included.	Predominantly secondary care services, though self referral and referral from primary care, social services and criminal justice system are also possible.	Two part-time psychoanalytic psychotherapists, two half-time psychotherapists, two full-time outreach workers, one clinical psychologist, one part-time secretary, and a part-time Expert by Experience (0.6 FTE).	The day TC offers accesses to a group-based treatment programme and peer support within the framework of therapeutic community. People who want to receive a service but are unable to use the day-TC receive follow-up from outreach workers. All those taken on by the service have access to internet-based peer support.	Up to 80 service users with up... attending to day treatment programme. Length of interventions is tailo... individual circumstances but i... generally around 18 months d...

| Leeds Personality Disorder Network | To reduce stigma and improve the management of people with PD by taking on clients for assessment, treatment and care coordination and enhancing the capabilities of staff in other services through support, supervision and training. | The network has a central base but staff working for the network spend most of their week working within other health and social care teams | The service aimed to work with people with PD for whom existing services had tried to help with limited success. Local services were asked to prioritise referral of people who were on enhanced CPA, had a history of poor engagement with services, experience high levels of mental distress and presented some form of risk to self or others. | Predominantly secondary care services. The service was also open to referral from social services and criminal justice system. | The Network had 27 staff members (22 FTE) including: a clinical team manager, a psychologist , assistant psychologist three half-time psychotherapists, 2 voluntary sector workers, an occupational therapist, two half-time probation officers , two accommodation support workers, an advocate, a user/self-help worker and administrative staff. | Assessment, care planning care coordination. Outreach - individual sessions offered in service users homes or at other resources in the community.

The content of individual sessions is guided by five therapeutic principles described by W John Livesley (2003). The network also runs time-limited group based interventions based on CBT, DBT and psychodynamic psychotherapy. | Care coordination for up to 45 users.

Length of intervention is not s but intended to be long-term. |

Icebreak	To target people aged 16–25 who are at risk of social exclusion but not necessarily diagnosed with PD. To improve social cohesion and social capital; provide new services driven by client need; support carers and dependants and ; promote a 'more positive experience of life'.	The service runs from a youth counselling and advice service (the Zone) which is a highly visible shop-front premises within walking distance from Plymouth city centre	Aged between 15 and 25 Registered with a GP in the local area Significant interpersonal problems/ at risk of social exclusion The service will not work with those who are already receiving input from adult mental health services.	Predominantly social care and the local youth advisory service. The service is also open to referrals from child and Adolescent Mental Health Services, Youth Offending Teams and other elements of the criminal justice system.	One team leader, 6 FTE care coordinators, 0.2 of a GP with special interest in mental health and input from a consultant psychiatrist from Plymouth psychotherapy services. Care coordinators generally have a background in mental health nursing, youth work, counselling services and creative therapies.	Individual counselling, advice and support. Assertive outreach, when indicted. Referral on to other services including counselling, education and training and social services.	To case manage up to 35 pe... provide advice and support to... others. Length of intervention is not s... but long term support is availa...

4 Overarching themes

4.1 Service providers

In this section we explore some of the dominant themes that emerged during interviews with managers and staff working in the 11 pilot services.

4.1.1 Organisation of services

Service development

The principal factor that appeared to determine the structure and philosophy of pilot services was the expertise and capacities of the lead clinician(s) and their partners who put together the application for funding. This is, as one might expect, given the absence of evidence about the optimal organisational structure of a dedicated service for people with PD. Plans for the pilots were strongly influenced by the Department of Health brief, which asked services to provide both direct services for people with PD and to include methods for supporting others in their work with people with these problems. As a result, nine of the 11 pilot services were loosely based on a 'hub and spoke' model: an intensive therapeutic hub addressing the needs of individual clients, together with some commitment to enhancing the capacity of voluntary and statutory health, social care and other agencies around them to work effectively with this user group.

Where pilot services were based on an expansion of an existing service, such as The Haven, feedback from existing service users influenced the development of the proposal. However, there was little evidence of service user involvement in the development of most of the innovative services, where structures for involving prospective service users rarely existed (see Section 4.1.7 below).

The bids did not entail detailed estimates of the numbers of people in each area who had PD. While some services had attempted to gauge levels of PD among those in contact with mental health services, very little was known about the extent of PD among people not engaged with mainstream mental health services – the very people whom several services wanted to try to engage. The capacity of the pilots was, then, not clearly linked to need, but to available resources.

In recognition of the heterogeneous needs and capacities of people with PD, most of the pilots set out to provide a range of services. Provision of more than one service or treatment option also enabled most pilots to present a choice to potential service users, a capacity that many believed important in promoting engagement. These options included case management; support in engaging with vocational and social activities; outreach, in which individual staff go to the users; groups to consider choices of therapy; individual assessment and treatment formulation by a therapist; one-to-one therapy, psychodynamic or psychoanalytic or psycho-educational, DBT or CBT; peer support; group therapy, skills-based or psychodynamic, and community participation, whether structured, as in TCs, or more casual, as in drop-in.

Most of the pilots offer more than one type or 'intensity' of approach. Several of the pilots recognise the value of combining individual therapy sessions with group work. There is a general recognition that 'one size does not fit all'. Those services that offer peer-led social support encourage service users to bring in a range of practical and social difficulties: advice sessions are available, the groups have access to phones to support service users to deal with issues during the group, and service users are encouraged to run their own Care Programme Approach (CPA) reviews and to plan appropriate action. Integration with the Care Programme Approach is managed by the pilots in different ways: there has *not* been a straightforward adoption of CPA procedure – common within community services and recommended by NIMH(E) (National Institute for Mental Health, 2003b).

In the last funded year of the pilot process, staff were increasingly reflecting on the needs of different types of service user, and devising interventions which might improve life for those who appeared unsuited to the current model. Some of this mismatch related to overly intense interventions where resources could be better expended in a more diffuse way over a larger group of service users. At least three of the pilot services are offering or planning to offer interventions around parenting, aimed at women. We were told that responsibility for parenting is overwhelmingly that of women: 'the men are either dead or gone' (S4). Staff told us that, as parents, service users do not have good experience of parenting to draw on, so may do poorly in general parenting classes.

> It helps parents to talk about their anger, shame and disempowerment, to say some pretty ghastly things and to reframe these. The sense of empathy can be very profound. (S4)

Target population

Within their remit of providing services for people with PD, most of the pilots aimed to be inclusive. Despite this, several had formal exclusion criteria concerning capacity and the need for some indication of motivation to engage in therapy. Presence of a psychotic illness, use of medication or uncontrolled substance misuse, the presence of significant learning difficulties, and past history of significant violence or aggressive behaviour were the most common exclusions. The extent to which pilot services require people to have a diagnosis of personality disorder varied: one service which aimed to work with young people before they came to the attention of mental health services did not use this terminology; a pilot taking referrals from primary care relied on the judgement of GPs; some of the pilots that were open to self-referral effectively worked with self-diagnosis; while some of the services that deliver structured psychological therapies instituted formal procedures for diagnosing PD. Staff at most of the pilots told us that they worked predominately with people with Cluster B and C, with Borderline PD, the most common diagnosis.

In contrast, most services reported that they did not work with people whose foremost diagnosis was antisocial personality disorder (ASPD). Reasons for this included doubt about whether interventions they were providing could help people with such problems, and concerns about the risk to others posed by people with this disorder. Although several pilot services take referrals from probation services and two of the networks have probation officers on their staff teams, work with people with ASPD has been limited to advice and consultation delivered to probation staff.

Services also varied in their capacity for working with people with co-morbid Axis One disorders. Nearly all work with people with eating disorders and substance misuse problems, but none would take on service users who were dependent on alcohol or other drugs. One pilot service was set up to try to meet the needs of people with PD and substance misuse, but the threshold for accepting a referral was lower than would qualify a person for substance misuse services.

> We decided that it had to be problematic to their mental health, and that wasn't problematic in relation to alcohol and drug [service] standards. So our criteria was that when they misused it, it was problematic and that within the last six months. So there are some people who managed to not drink for three months and four months but it's still there, still a problem. (M32)

Other pilot services also provide help with substance misuse problems, which were reported to be common among referrals. Several services sought to work with people with 'severe' PD but did not define what was meant by this. One service planned to offer intensive case management to 50 people, and instructed the local community teams to refer:

> The people who are most difficult, the people who you worry about, the people who present the greatest level of risk and greatest challenges to yourself… the clients who are beyond the reach of the CMHT, or have exhausted the CMHT resources. (M53)

There were no structured measures of severity of PD in any of the service criteria: here and in other services, this approach was designed to prioritise those people with whom mainstream staff were most 'stuck'. In this service, a comprehensive assessment process required that referrers demonstrate that they were unlikely to be able to move the person forward. Other services, including the TCs, sought to engage not the staff, but the users directly, minimising entry criteria so that a diagnosis of PD was not required. The potential service user's ability to make use of the therapy, their commitment to engage, and in some cases the views of existing service users, have been driving eligibility for the service. Both approaches appear to have attracted people with a range of different functional abilities and support needs.

Staff at most services believed that they were working with people with different levels of severity. Services characterised by peer-led group interaction told us that this was useful, as the more able might support the less able, and people could model their progress either prospectively or retrospectively. Services concentrating on more complex cases appear to be more likely to specialise in one-to-one work, at least in the early stages of therapy.

Staff at pilot services told us that mainstream services found it difficult to assess personality status or consider the psychological needs of people who are unable to communicate effectively in English, because of the difficulties associated with trying to conduct in-depth assessment.

Source of referrals

Most pilot services saw community mental health services as their primary source of referrals. Almost half were also set up to accept self-referrals. Some service leads felt that self-referral was an important means of being able to respond positively to people with PD who had made a decision to make some sort of change in their lives, and others felt that self-referral was important as it could enable people who had been excluded from mainstream mental health services to access the service. Specialist secondary services, primary care services, Emergency Departments, and social care services such as housing teams were also seen as likely sources of referral. In the early phases of the funding, most pilots visited such teams and put together written information to describe the services and who could apply, with much of the material being aimed at service users to supplement discussions with staff. Service users – from other services where the pilots had not yet recruited – were often involved in developing written materials. These were seen as key tools in engaging service users, and in presenting the philosophy and approach of the service. The use of terms such as 'personality disorder' was widely debated in these contexts.

One service relied almost exclusively on referrals from primary care. As a general rule, staff suggested that GPs were not able to reliably discriminate between PD and other long-term mental health problems. GPs were also inclined to see the emotional distress experienced by people with borderline PD as evidence of clinical depression.

Key messages – service organisation

Plans for pilot services were developed on the basis of the expertise and capacities of lead clinicians in consultation with other service providers. There was little formal assessment of local needs or, with a few notable exceptions, involvement of service users.

Pilot services offer varied and flexible services: many have several options with which clients can engage. Choice and flexibility tailored to client needs are key values.

Most pilots work with a variety of clients, with different types of PD, and different levels of difficulty. Rather than confusing treatment approaches, this variety is reported to be useful, especially in models relying on peer interaction.

While few services have formal exclusion criteria, people with antisocial personality disorder, dependence on alcohol or other drugs, and those unable to communicate in English are generally excluded.

4.1.2 Delivery of services

Generic factors when delivering dedicated services to people with PD

Staff highlighted a number of common themes around working with this group. These themes were reported on numerous occasions across pilots where different types of services were delivered. Staff believed they were generic issues and should be considered by all those delivering dedicated services to people with PD. They included:

- The service should be realistic in its aims, and not claim to undo prior abuse, neglect or experience. 'We cannot change the future or repair the past.' (M32)

- Attachment and the development of trust are important to all models, although the object of attachment may be the service or group, or one or more individual therapists (see below).

- Goals of therapy should be negotiated with service users. This requires a flexible and client-centred approach to outcomes.

- It is useful to distinguish between long- and short-term goals, so that service users can identify and acknowledge their achievements, but also be aware that they are moving toward 'larger' aims, such as preparation for leaving the service.

- The person should be treated in such a way as to confirm that they are valued and valuable. The response to service users and their disclosures should be non-judgemental.

- The person should be treated in such a way as to encourage self-acceptance – among people with a high degree of self-loathing this was considered a key goal of therapy.

- The approach should be validating, rather than dismissive, of the person's experience. Service users should be encouraged to see their feelings as real and reasonable according to their circumstances and the difficulties they have had to manage.

- Staff may lead or facilitate, but the general approach to leadership is by example and suggestion rather than control, with a view to empowering the individual service user or group to identify and manage their difficulties.

- Efforts need to be made to help a person develop emotional regulation: 'to help clients express feelings and find ways to speak that aren't emotionally devastating' (S61); to enable service users 'to stay with the mental state for seconds rather than reacting in a traumatic way'. (M45)

- The service user should be encouraged to live in the moment, the here-and-now. Agonising over the past or future is likely to be counterproductive. 'Not about changing circumstances, so much as changing the meaning of life events.' (M45)

- Thinking can be more important than doing. 'There is something about psychoanalytic training that helps you to persist with something and to keep thinking about something rather than having to do something.' (M38)

- The service, led by its staff, has to be able to sit with negative, uncomfortable, demoralising feelings: 'For a while, you have a patient who is compliant and apparently then able to think. But… I don't think it lasts, I think you have to be able to deal with the very negative aspects of the relationship as well, where you don't actually move these people on.' (M38)

- The service should offer the user 'containment': that is, a secure base within which they can acknowledge feelings without falling prey to their destructive power.

- Staff working with this group are also prone to potentially destructive emotions, such as anxiety and antipathy, and they also need mechanisms to identify and express them within a 'contained' environment.

- Whether formally or informally, the service should offer skills that can be used to promote better lives and which the person can utilise independently of the service.

- Many of the pilot staff talked about encouraging self-awareness of psychological processes, states and emotions. Whether the interpretation was given in terms of mindfulness, emotional regulation or psychological thinking, there was general agreement that therapy for this group needs to act upon a person's ability to identify and manage the responses of themselves and of those around them.

- Consistency – across time and between personnel – is a key value, not just because it reduces the potential for chaos but because it gives service users, and staff, security.

- Comprehensive communication within staff teams is seen as vital. Services should have a clear information-sharing policy, communicated to the service user at induction. Most teams insist on the right to share information within the team, or within the community, and remind service users of this if personal information is disclosed.

- Group or community settings are valued by all services because of the power of peer support and the opportunity they offer for practising relationships (see below).

- Discharge or disengagement from the service is likely to be difficult and threatening for some service users: it may be viewed as abandonment and may precipitate an increase in behaviour designed to demonstrate need or risk. Some services address this by working toward discharge or self-sufficiency as a specific goal at a specific time from the point of engagement, while others have provisos for re-entry into the service. Some services are developing models for less intensive, ongoing support so that discharge need not be absolute.

Attachment, trust and sharing

The extent to which attachment to an individual worker is woven into therapy varied between pilot services. In the context of one-to-one work, the therapeutic relationship is very much seen as a tool of both engagement and therapy. In TCs, on the other hand, the member is encouraged to attach to the group or community, through which as much as possible of the person's difficulties are submitted for processing. One of the proponents of this model said:

> It's a much better way for the onus of support not to fall on one person: it's safer, more containing, if it falls on the whole TC. (S65)

A mid-point is where service users are encouraged to feel contained by the staff team, not the individual, giving both staff and service users different options 'if key relationships become a bit ragged' (S15), or if staff members leave or take holidays.

The theme of attachment, and who the service user is held by, is closely linked to policies governing confidentiality. For the safe containment of anxiety, and to facilitate support, almost all the services shared information between staff.

> We tell them from day one, and whenever it arises that we cannot have confidences with them: that if they tell one of us, the whole staff team has been informed. (S64)

Services based on community or group provision also encourage members to communicate with the group as a whole, not with individual members. Whoever was included in the sharing of information, there was agreement that 'secrets are bad' (M11) and have the power to isolate the individual and prevent recovery.

Peer support and group work

Peer support is an integral element of pilot services based on the TC approach but is also an important part of service provided by several other pilots. Staff told us that other people can provide an important means of self-validation, act as role models and help a person to develop tolerance of others. With the exception of a single manager, who stated that group work increased the likelihood of service users damaging each other, most providers subscribed to the value of group work, albeit in some cases alongside one-to-one sessions.

> It's ideal to learn the skills in groups because you get to share other people's experience and recognise that you're not the only one struggling with these things… most people can see faults in other people before they can see them in themselves. And they get that 'yeah, so you can see that in them but oh my God, do you think I do that too?' So it does speed up the process. And it's cost-effective too. (M33)

However, not all services had been able to engage service users in group work: in the first few months of their development some discontinued groups through lack of attendance. The use of groups is perceived differently by different services. For example, in one pilot, individual sessions were seen as providing a means of helping people use groups to best effect. However, in the TCs and the Service User Network, users are asked to bring *everything* that impacts on them into the group, subject to that person's own ability and desire to share it.

Groups need to be managed by experts, although the input of staff may be difficult to identify. Suggested roles include the moderation of interaction, so that vulnerable people are not incapacitated – one worker described her role as to 'soften the edges' (S19). TC workers have expressed their function as 'containment', and 'keeping the group safe'.

Combining different interventions

Across the different pilot services social activities were seen as important in helping people develop skills and increase self-confidence. Involvement in structured activities was also seen as an important means to combat social exclusion and stigma. Even in pilots that specifically aimed to provide psychological therapy for people with PD, social and other occupational activities were seen as central to the success of these interventions. One provider pointed out that structured activity is an inherent part of the DBT model that is often neglected. Several services aimed to intersperse psychotherapy sessions or groups with social activities, as a means of developing capacity to deal with conflicting emotions:

> It was really difficult for people initially… to say, play a game or, you know, to even be happy. It was like they daren't laugh because if they laugh it's saying, 'I'm alright, and I'm not', so the [mixed] agenda plays an important role. (S65).

Many of the services promote the use of mainstream social and leisure facilities and build them into care plans: 'We are now sending people to the gym: there is value in these low-level interventions.' (M1) One pilot was primarily concerned with the provision of vocational support to patients referred through, predominantly but not exclusively, primary care, with a focus on combating social exclusion and the stigma of mental health services.

The mixture of the pragmatic and the psychotherapeutic in these services is innovative, and requires staff to take on work that previously they could leave to some other service. For example, psychotherapists and advice workers have been brought together in the same teams and with the same service users and, in some circumstances, either could be delivering interventions that relate to both areas. Finding a common language and common values has been difficult.

The education and skills facilitators are both social workers – and what they would call therapeutic is different from what psychotherapists would call therapeutic… sometimes that's created rumours, battles in the team or lack of understanding of each other and we need to do a lot of work on that to be able to keep talking to each other, to value the fact that people have very different perspectives and all the perspectives are really important. (S47)

The development of advice services for service users among the pilots was not a prominent part of the bids, and it is instructive that so many of the pilots have become not just educators, trainers and consultative partners with service providers, but are also working directly to improve the practical skills of users.

Specific therapeutic models

Most of the pilot services set out to deliver innovative interventions for people with PD that have not been attempted before. Exceptions to this were services providing TC-based intervention and one that delivered DBT. While several pilots stated that they provided groups which were 'DBT-informed', only one pilot ran, from a menu of options, a rigorous DBT programme. This placed particular demands both on staff and service users.

DBT, it takes commitment and it takes intelligence and a intellectual capacity, so people need to want to change to commit to DBT. They need to agree to the targets that we put forward because the hierarchy is that suicidal thoughts and self-harm are the first priority, you don't go anywhere else until that's sorted. Now there are a lot of people who don't want to stop self-harming, so DBT is not for them. (M33)

Pilots included several day therapeutic communities: none was residential but they achieved a high degree of consistency through the guidance of shared consultants, staff and service users, and the Association of Therapeutic Communities. A TC is:

A safe and secure environment, a place of safety, where people can come and learn how to make relationships. (S65)

It creates an environment where people engage in normal interactions that trigger behaviours and feelings they have difficulty with: it's got to be an emotionally safe environment, where they can reflect on and interpret those feelings, so they don't have adverse consequences. (S41)

In TCs, staff aim to 'contain' the anxiety in the group, maintain boundaries that keep the community safe and soften the impact that service users may have on each other. In order to allow the community to take responsibility, staff intervention is minimised. Community members learn to recognise the need for, and to arrange, support for each other, but this is one of many capacities that develop as the community matures. The model of democracy and accountability in TCs is difficult for people to grasp.

It still feels very much like it's a staff role to reinforce the boundaries of behaviour that are therapeutically helpful or that we can work with… The community not being quite robust yet. I mean people are starting to question things and each other and boundaries… So we're now going through a bit of a stage of being the enemy at the moment, bad parents and that's only a natural part of the process. (S62)

Eventually, members should take over enforcement of rules.

All the pilot TCs are part-time, operating between one and four days per week. Staff stated that there may be advantages to the part-time model: 'people get the chance to practise skills' (M38), and there may be less tendency to drop out of TC services because they are largely confined to school and work hours. However, all of the new pilot TCs have acknowledged the difficulty of importing the TC culture within the time limits of the pilot funding. One of the key sticking points is the assessment and voting in, or rejection, of potential recruits by the members.

Key messages – service delivery

Despite differences between types of treatment, and different formats in which they are delivered, there is broad agreement about the basic parameters for providing services to people with PD.

In addition to providing or facilitating access to psychological therapies, dedicated PD services may need to provide advice and information, psycho-education, and ensure people have access to social and occupational activities.

With the exception of Dialectical Behaviour Therapy and Social Problem Solving the impact of interventions delivered by pilot services has not been examined in randomised trials.

Group work and peer support are seen as valuable interventions that are believed to support self-validation and help people develop insight and tolerance of others.

4.1.3 The service user's journey

In this sub-section we highlight some of the factors that staff view as important when service users are referred to, start attending and leave services.

Finding the right place

Most of the pilots expressed commitment to considering the individual's needs in a broad sense: the interest of providers went beyond recruitment to their own service, and assessment, advice facilities, pre-groups were built into most of the pilot models, often at the point of first contact. Some services shared a single access point with the psychological therapies, or psychotherapy, service; another was attached to a walk-in advice service, and another, offering distinct interventions, has chosen to establish its own advice service to give applicants a better introduction to the available options. Some services, such as the early intervention service, attach value to keeping service users out of mental health services altogether if possible. Only one of the pilot services was set up to take referrals from primary care. Unfortunately, because of the model of stepped care in the Trust, there were barriers to primary care staff wishing to refer patients directly into a tertiary service, such as a specialist psychology service for people with PD.

> Have a real problem in getting through the cycle of exclusion: GPs who identify suitable patients cannot refer to [tertiary psychology service]: they have to refer to the CMHT and get them to take person on… so we cannot keep clients out of mental health services: and CMHTs can say they won't take them, as don't meet their criteria. (S29)

A universal requirement of those pilots that worked directly with service users was that they were informed about the nature of the service and, by implication, about the nature of their problems. This did not necessarily mean that pilots adhered to the term 'personality disorder', as several rephrased their literature in less medical terms.

Engagement

Staff working in pilot services told us that little things can make a difference when trying to engage people. One therapist told us how they put smiley faces on appointment letter envelopes to distinguish them from post a service user states she cannot face opening. Another service provider told us how one person would only respond to text messages during the early phase of engagement with one of the pilot services. Having access to a waiting room and a kitchen – or a room shared with staff – can make service users feel more at home when they come in for appointments. Knowing different members of a team can help, because it allows substitution when therapists are away, but it is also friendly and respectful.

> It's not appropriate if I inundate them with appointments… but I want to know them. I tell my staff, 'if I'm in the corridor when you're going in and they have appointments, introduce me'. Nobody solo works, that clients do get to know… and if they're linking into other groups, they are getting to know other facilitators because all our groups are run by two facilitators. (M33).

Staff spoke of working hard to overcome the potential 'us and them' division which they feel is common in patient-professional relations within health services. One way of doing this has been to share results of any screening or assessment tools that services have used. For instance, one pilot service that routinely used a standardised assessment tool shared findings from this in order to provide feedback to service users about the difficulties they reported experiencing: the template was then used to help with the development of a care plan. Similarly, one service routinely discussed psychological treatment options, so that treatment was a partnership.

> We normalise diagnosis and I believe that we work through the stigma component. And in doing that diagnostic stuff… this starts to make sense of why I'm experiencing those things and that it's not abnormal, it can be defined… then there's something you can do about it. So it's very containing I think for people because they've all been sold the story, 'there's nothing you can do for PD'… if we work on these theories and support you in this way, you can start to work through these and they'll be less problematic for you. (M33)

Services highlight a number of ways in which engagement was facilitated:

- allowing self-referral

- having a facility permitting immediate 'drop-in' casual attendance

- not requiring lots of forms, and assisting service users to fill in the necessary paperwork

- having two staff involved in early assessment, with one from the service whom the user was guaranteed to work with in early days of therapy

- offering alternatives, including referral to other services

- making information exchange two-way, so that people knew what to expect and were responsible for deciding to engage or not

- self-help groups

- offering contact with existing or ex-service users

- integrating client-identified goals and desires into therapy goals.

> What is important to engagement of this group, who are often mistrustful, let down? One: honesty. I'm always shocked that people come back because I [tell them] I can't give you anything really, I can't offer any definite guarantees. Two: I also think the not wanting to make it better – which is the natural impulse, if somebody's talking about suicide or self-harm, not trying to make things okay because that's more about us than them. (S50)

Several of the services use assertive outreach techniques, particularly when trying to engage people with Cluster A PD. Several also prioritise service users with high needs and make considerable efforts over time to engage them, but staff admit that there must come a point when such efforts must be seen as unproductive and a waste of scarce resources.

Assessment

Some pilot services stressed the thoroughness of their assessment practice. Several staff discussed assessment as simultaneous to engagement: it might then take months, as trust and communication developed. 'We often get to know the person better than the referrer does' (S58). Assessment may then be an intervention in its own right (M54). The services that placed greatest weight on assessment employed strategies to reduce attachment, so as to reduce trauma associated with detachment and disappointment. However, the most common reason cited by services for not taking clients following assessment was the person's lack of interest in changing: 'Sometimes they have their way of doing it and they're not really interested in a new point of view…' (S48). In contrast, two of the pilot services providing case management for people with severe PD agreed to take on service users whether or not they were motivated to try to make changes. The aim of these services was to provide high-quality support and to try to promote interest in other interventions, following a period of stable engagement.

In contrast, those services offering structured therapy need to assess the individual's ability to benefit, their capacity and vulnerability. Would the person manage, during and after, group work? Were their basic needs sufficiently met to benefit from therapy? Were they too frustrated by external issues, e.g. conflict with family or neighbours, to concentrate? Could they benefit from skills training to manage problems such as self-harm, in order to reach the point where they might manage psychotherapy? Many services highlighted the difficulties faced by service users when confronted with the prospect of group work. Some of the services offer individual sessions to prepare new service users for this work. In contrast, some of the day TCs did not assess service users as fully, seeing preparation groups as a better means for the individual and the group to assess their ability to make use of the TC.

If people referred to pilot services were not subsequently taken on, teams still tried to provide something of value – alternative options, or an invitation to re-apply in the event of particular changed circumstances – to them or to their professional carers.

Transfer of care and CPA

Pilot services varied in whether or not they took on CPA responsibilities for people using their services. Some services were specifically set up to take on case management of people with PD and saw taking on CPA responsibilities as a central part of their work. Others preferred to keep the service user under their previous care coordinator and psychiatrist. One service manager stated that taking on CPA responsibilities could lead to dependency, and that by not taking on care coordination the service was able to distance itself from medication and the 'abuses' of mental health services. Other pilots took on service users who were not currently on CPA and believed that registering them for this could be stigmatising and counter to the aim of helping them move away from contact with mental health services. Not all services offered long-term interventions: transferring CPA responsibility during a 16-week skills course, for example, was not appropriate. Service managers also highlighted the additional administrative burden that taking on the role of care coordination implied, and felt that time would be better spent delivering psychological therapies and other interventions. Others argued that it was a mistake for dedicated services for people with PD to distance themselves from CPA.

> It was assumed that, to be this psychotherapist, they have to be 'hands off' from all of that nitty-gritty. As though CPA had to be the 'coercive' part of medical model. And I actually think they're wrong. I think to be the psychotherapist, to be involved in the nitty-gritty, you can have a much better outcome. (M46)

Staff at this service told us that it was important to combine what were traditionally seen as CPA responsibilities and the traditional psychotherapeutic role. They argued that this enabled staff to take a holistic approach to people and to develop a better understanding of how their lived experience combines the practical, the emotional and the psychodynamic, and that care services should also do this.

Another reason for taking on CPA responsibilities was that in most areas referrers expected pilot services to take on this role. Some staff working in pilot services felt that it was important for the service to take on CPA responsibilities in order to maintain credibility and support from hard-pressed CMHT staff. Service users were sometimes referred when it was felt that care provided by local mental health services had been unproductive, and referrers were keen that responsibility for care coordination was passed over to someone else.

A common model among the pilots was to request continued CPA coordination from the existing provider, with responsibility to be transferred when the client had 'settled' in the service, provided that the therapy model was of sufficient duration. Some services, including the TCs, wanted the individual to take on their own CPA coordination, with a view to withdrawing from the register as they became more self-reliant.

Retaining service users in the service

Staff working in pilot services told us that retaining people in services was difficult because of the ambivalent feelings towards others that many people with PD have. People may also leave a service prematurely in order to avoid or control what they fear will be the trauma associated with discharge. Abandonment is a common experience of people with PD. In order to mitigate the possible impact of staff absence, most services that offer a key working relationship with a staff member introduce at least two key staff. In some services, those in early contact with the service user at the assessment and engagement stage will plan to be involved in the therapy stage.

> [We] make a commitment that [one of the two people] who do the assessment will be coordinating the group, so that people do know someone when they start. (S63)

Most services have some rules or boundaries around attendance, and challenge non-attendance. In community or group services, members were encouraged to phone in to explain absences, and group members might phone out to check on absent members. The process may include occasional communications, quite commonly from the group or community, to show that the person is 'kept in mind'. Staff reported that this seems important to people who may feel particularly excluded and not valued.

Staff told us that when users have disengaged from a service, people are given written notification that they can no longer use the service, together with information about how they could go about re-entering or re-applying to join.

There is a difficult balance in all the services in setting treatment goals and personal challenges that are meaningful achievements, but that do not set service users up to fail.

All services have some rules about behaviour that will instigate discharge or suspension from the service. In user-led services, rules are designed by the group or community, and typically relate to attendance, use of substances or dealing drugs on the premises and aggression. Expulsion or suspension for infringement of rules sanctioned by members was usually felt to be a positive part of therapy for the individual concerned and for the collective. More difficult to codify and enforce are rules governing communication: casual talk about self-harm may be detrimental to other clients; the development of relationships between service users outside service premises may be common, but rules may be in place discouraging the expression of such ties in the service. Conversely, in TCs, there may be a rule that any contact is brought into the community and openly aired. Several of the pilot services also have guidelines governing staff–client interaction, such as limits on the amount of time clients can spend in one-to-ones during crises. Ideally, user-led services should take over the administration of discipline in relation to breaches of rules and attendance, so that the staff do not always take on enforcement roles. Consistency is highly valued. User-led services, it is hoped, take on increasing responsibility for enforcing boundaries, such as attendance without staff support, as they mature. However, there may be times when staff are in the difficult position of knowing of good reasons why a service user is breaching boundaries, but being unable to advocate for exceptions because the client's circumstances are confidential. Where staff alone have responsibility for rules, there is the possibility of more flexibility in individual cases.

Paying travel costs or facilitating transport is important in encouraging attendance, and vital in some rural areas. A staff member at a rural TC told us of a service user who left the service because she felt she was too upset to drive home safely after groups.

Discharge process

Because most of the pilots work with people for long periods of time, and this evaluation was conducted within the first two years of their operation, many providers had limited experience of discharging users when these data were collected. Staff told us they were sensitive to how difficult endings were for many people with PD, and that the process of disengagement therefore needed to be planned carefully. Several services told us of plans to develop a phased discharge aimed at minimising feelings of abandonment. Some staff said that it may be more productive to keep people on caseloads with minimal contact rather than to discharge completely.

> [We] need to be prepared to work with a person for a long time… discharge can totally destabilise a person with attachment problems: to avoid what they see as abandonment, they will escalate unstable presentation. So don't discharge them, you can maybe see them less often. (S10)

Some of the pilots did not fully consider limits on capacity as a driver of discharge until they reached capacity. A service that does not have the ability to discharge people may inadvertently deny others access: those that can should be moved on, and it may be helpful, as is common in many services including therapeutic communities and some psycho-educational groups, for a timescale to be set from the point of engagement. Some staff of open-ended services felt that there should be a cut-off point, and that allowing ongoing use of a service encourages dependence and reduces motivation and the development of coping strategies for existing clients, while denying others the opportunity of using the service.

> Within three months we should work towards leaving… the project will have failed if we can't move them on. (S14)

Some services are also exploring the role that service users might play in running ongoing peer-support groups for people who are no longer in contact with service providers.

> I think we try to get people to a point where they can get by without very much at all from services: but there is an enormous gulf between minimal input and discharge. (M8)

Key messages – the service users' journey

Pilot services take different approaches to the use of the term 'personality disorder', but all aim to be explicit with service users about the nature of the person's problems and the limits of the service they are being offered.

Pilots use a range of techniques to foster engagement; some allow self-referral, others provide opportunities for informal contacts with service providers and most are keen to share information during the assessment process.

Pilot services varied as to whether or not to take on CPA responsibilities for clients. For some services delivering relatively short-term interventions, this was considered impractical. For others that deliver interventions over longer periods, CPA was seen as a way of actively involving people in reviewing their care.

Pilot services work hard to achieve retention in services. However, they also emphasise that attendance is an active choice. Most pilots provide those who choose to leave the service with information about how they can reapply to the service in the future.

Pilot services appear to have given less attention to how people will leave these services. Plans for follow-up groups and other sources of support were still being developed at the time of this study. As services reach capacity, more attention will need to be paid to moving people on.

Most pilots take on CPA responsibilities once it is clear that the client will remain in the service. Their approach to CPA can be innovative, placing more responsibility on the client to coordinate their care.

4.1.4 Managing crises and self-harm

General approach

Pilot services have attracted a large number of people who regularly self-harm. A key theme in addressing these behaviours is to discourage dramatic responses and to have contingency plans in place, ideally equipping the individual to implement them before undertaking self-harm. 'Because crises are predictable, we can plan for them' (Minutes of Learning Network, September 2005).

It is a precept of DBT that the service user should be helped to develop strategies to avert self-harm before any more exploratory work can be undertaken. While tending not to draw on DBT discourse, most pilots prioritised this issue, helping service users to identify the pathways into self-harm and the warning signs, and develop alternative practices, such as seeking support and / or distraction of some kind. Pilot services avoid punitive or disapproving responses to self-harm and place emphasis on alternative strategies, or upon the value of the person.

> If you did that to someone else, or someone else did it to you, I would have to take measures to stop it, it would be against the law: so I can't condone it just because you did it to yourself. (S4)

There is general recognition that no external agent can stop a person self-harming: responsibility lies with the only person who can change course of events, the service user themselves.

> Putting self-harmers into hospital on suicide watch backfires: it takes responsibility away from them. It is better to talk to them about how it comes about and find something to divert them from it. (S5)

Staff from several pilot services have commented that self-harm becomes less scary once you know you can talk about it openly with clients. Opening an un-emotive dialogue with the person about their behaviour was reported by staff – not all of whom had clinical backgrounds – as useful.

> If you have a sense of – an ability – to communicate, risk can often be minimized. (S50)

Mainstream providers, it was said, might avoid a topic that is manifestly uncomfortable and unpleasant, but staff reported increased confidence in managing their own anxieties, and reducing the risk of repetition, if they talked to the person about it:

> What happens often is the responsibility is handed over to the care staff. Getting into dialogue with the patient about the conflict within themselves about their self-destructive behaviour and enabling them to take charge of themselves again can be phenomenally useful… you can then get into a negotiation rather than an action–reaction dynamic. So both feel they have more control in the situation. (M8)

Working with people with PD appears to involve acceptance of some level of risk. Among the pilots, risk to self was relatively commonplace; while people, felt to represent an active risk to others, were often rejected at the referral stage. None of the services took people who had perpetrated violent crimes, although information around criminal behaviour, if not known to the referrer, would usually have to come from the client. Asked about risk assessment, providers did want to know the worst, and to plan with the client to manage that if it recurred.

> Gate-keeping relies on an old-fashioned view of risk… the most useful thing to know is the worse thing they've ever done, as bad as they've ever been... there are no settings in which the risk falls to zero. By turning them away, we're not helping the patient: the most ethical thing is to recognise need and to take the most seriously unwell that we can. (M1)

24-hour support

In recognition that crises can occur at any time of day or night, pilot services had developed a range of different approaches to helping support people outside of normal working hours. These included: telephone contact with staff; access to a crisis centre and crisis beds; peer-support structures, including telephone contact and contact via an internet chat-line; and crisis plans devised by service users and reviewed by groups. Where pilot services did not provide out-of-hours support directly they provided information to service users about existing sources of 24-hour support such as local crisis teams and home-treatment teams.

Pilot services such as some day TCs and the Service User Network have developed comprehensive protocols outlining how service users can obtain peer support at times of crisis. These plans initially met with resistance / anxiety among some senior Trust personnel, despite the likelihood that such protocols, arguably, result in less risky and more supportive contact than the unsupervised contact between service users which might otherwise occur. Specialist legal opinion was sought in one Trust before the protocol was accepted. It is ironic that services that do not acknowledge the 'unofficial' contact known to arise between service users in crisis may consider themselves less culpable in managing risk than user-led services that seek to govern that contact.

Many crises occur outside 'office' hours. Staff report that service users may initiate crises outside normal working hours in order to provoke a response that breaches the accepted boundaries of everyday care. 'Preventive' day services, versus 'reactive' overnight crisis services may require different approaches and it can be difficult for the strategies and boundaries enforced by day staff – including the crisis plans devised by the user – to be implemented in the context of a seeming emergency. Most services, whether or not they had a crisis support component, had an interest in devising shared protocols with local crisis and home-treatment teams, and some would make specific arrangements, with the user's knowledge, over evenings and weekends. One pilot was offering training to Samaritans to support consistent approaches to people with PD.

Approximately half of the pilots did not have an in-house facility for out-of-hours crisis support. In contrast, all of the service user-led pilots had or were developing some out-of-hours support system, though rarely did it run beyond two to three hours per night. The pilot delivering 24-hour services has developed a comprehensive range of methods to support people in crises, but has found the staffing of posts with anti-social hours challenging and expensive. Staff who can work anti-social hours may require longer breaks between periods of work than those in day services, and in a small service, continuity is difficult to sustain.

Some innovative approaches to crisis management

Two services among the pilots offer phone contact with staff outside normal working hours because it is an essential part of the therapy model; the TCs offer, or are developing, peer-support contact out of hours. In all cases, users are taught to use it only for specified purposes:

> It's not a crisis phone call, it's a support phone call… you really are trying to make a difference here, not just patch up the mess afterwards. (M33).

There is a sense that the availability of support reduces need for it.

TCs have user-led support as part of their remit. However, all the TCs in the pilot suggested that they needed to reach a certain level of maturity before members could coordinate and offer this service because it works best when both needs and responsibilities are shared over a larger number of members. One pilot, the North Cumbrian Itinerant TC, has pioneered the use of a website and message-board, P2P (or peer to peer). Staff members have access to P2P, but not to the message-board, and clients can be suspended from the website, so there are incentives not to abuse the facility. The facility was researched and developed to extend the TC, as members are dispersed over a rural area with limited transport. The set-top box doesn't need a modem. Guidelines include a ban on imminent threats or accounts of deliberate self-harm. The system allows the community's 'Top three' service users to monitor, access and delete entries, and a log is kept so that messages can be brought back into the community meetings. Staff suggest that the act of recording messages has advantages over phone calls because it introduces a slight delay which inhibits impulsiveness and allows a natural pause for consideration. Other services have suggested that e-mail messages to the service have a similar function, even though they will not be read until the next working day.

Key messages – managing crises and self harm

Crises can be anticipated and planned for and need not be viewed as emergencies. Pilot services manage crises and self-harm by engaging in dialogue with the person concerned, helping them to develop improved coping strategies, and avoiding drama and containing staff anxieties.

Methods for supporting people in crisis developed by pilot services seek to actively involve service users and tend not to provide an instant response. Service providers report that if people have been helped to prepare for crises, a delayed response can help ensure the service user plays an active role in crisis management.

Despite concerns about safety and feasibility, user-led out-of-hours support may represent the most viable type of support that can be offered by dedicated services for people with PD. Clear protocols are required governing who can provide and receive such support, how the contact should proceed and end, and how various eventualities should be met.

4.1.5 Staffing the pilots

General issues

Most pilots found it challenging to recruit staff during their setup phase; several service leads reported that some of those initially employed proved to be unsuited to working with people with PD. However, once services had become more established pilots generally managed to retain staff, and levels of staff turnover were lower than some service leads had expected. One manager recommended that probationary periods for staff working in PD services be made standard practice. When asked, 'What kind of staff work well with this client group?' most respondents said their answers were qualified both by the need to deliver their particular vision of the service, and by what they had learned from making mistakes. Professional background was said to be less important than personal qualities and the ability to engage service users. A minority thought it better to recruit staff from non-mental-health backgrounds as they were less likely to have preconceptions about the service and its users. This was less of an option where the service focused on delivering psychotherapy, requiring training, experience and aptitude: but even here, personal qualities were highly influential, and there were a fair number of workers – CPNs, social workers – from mainstream service backgrounds who wanted to change direction and develop psychotherapeutic skills. The downside of preferring personal qualities to qualifications is the amount of training needed at induction. Some of the qualities singled out include:

- The ability to engage service users, but not at the expense of neglecting appropriate boundaries.

- The ability to engage service users, but not at the expense of neglecting appropriate boundaries ability to empower users by letting them make some mistakes. Staff who are controlling were considered unsuitable for PD services. 'People with boundaries… with the boundary that allows them to not want to look after people, not want to get in and fix things.' (M33)

- Staff need to have a high degree of personal resilience. Staff who are vulnerable to resonance between their own and the clients' problems may be unable to work in this setting.

- Staff need to have emotional maturity: 'People who have an emotional maturity, a flexibility, a sense of humour, an ability to not take themselves too seriously.' (M33)

- Staff need to be able to accept the limitations of what can be done.

People do understand that we're very busy and they will get their turn… [But] there's more people needing something than you can give. You need to rationalise and accept that: there is a limit to what you can do. And there'll be clients that don't respond, and those that will die. You have to protect yourself and be realistic about what you can achieve. Our clients sabotage your best efforts at times, or go backwards. You can't take any of that personally. They're responsible for their choices. You need to respect that. (S14)

- Staff need to have a capacity and a willingness to reflect on themselves and their work.

  Somebody that has the ability to reflect on themselves… you know you can't ask the service users to be able to reflect on something if you can't do it. (M39)

  To work in a therapeutic community you've got to have a lot of self-awareness, you've got to be prepared to keep looking at yourself and I think a lot of other professionals don't want to do that. I think it's a bit scary for some colleagues in the other team, especially when we say 'how does that make you feel?' you can feel them backing off. (S64)

- Staff need to be able to discuss their own mistakes or uncertainty, as this is considered crucial to maintaining boundaries, security and containment of both staff and service users.

- Staff need to be able to balance their work life with other aspects of their life.

  The capacity to take a clear-eyed view of things and not be driven too often by hatred… someone who can maintain ego-strength, personal security. And all members of our team have substantial lives, go home to something as substantial as their work. (M1)

- Staff need to be willing to work as members of a team, to reach compromises and accept the process of shared decision making, and / or the decision of the clinical lead, when agreement is not possible.

- Empathy and non-judgemental approach, possibly borne of experience.

> I suspect that people who have had no emotional issues have had a genuinely wonderfully happy, fine upbringing with no complex issues, no emotional problems: why would they want to work in a service like this? (S61)

Recruitment issues

Staff recruitment was a challenge in the first few months of the development of several pilot services, especially those that were developing new and innovative services. Service managers reported that new staff sometimes wanted to carve out their own vision of the post, but did not, in their view, have the experience to know what was needed. Some then found the post did not fit their preconception of it; or that the post, since being advertised, had changed not only in title but also in content (examples: from community recovery to skills facilitator; from social inclusion worker to care coordinator). The training and setting-up phase, when therapists saw no clients but were used to publicise and present to CMHTs to recruit clients, was particularly difficult: 'It is hard for therapists not to see patients: they feel lost' (M45). There was uncertainty about new models of working: some of the TCs took staff who had no experience in this area, and the early days of working with clients were very challenging. Most services tried to recruit a mix of people.

> When we recruited people we'd rather have talent than experience so we had quite a few talented people but not many experienced people, so what you want in supervision is a talented, experienced person there who can recognise dangers and lead discussions about solutions. (S48)

In some of the pilots, the staff came from existing services within a local Trust: not all of these posts were replaced. This effectively meant that funding for pilots resulted in reductions to expenditure on existing services. It may be that Trusts see investment in a PD service as more politically imperative than, for example, the maintenance of an existing psychotherapy service. In one large pilot area, the pilot monies and services have initiated a full-scale revision of services: this is potentially positive, but in some cases, the gains made for PD services have represented losses for others. The Networks have also found that some anticipated secondments did not happen because staffing pressures on local services did not allow the person to be released. Training opportunities for local staff to spend time in the pilots have also been inhibited in this way. Service managers believed that these staff would have added something to the capacity and skill mix of the pilots, and to the dissemination of the model. One pilot set out to attract young psychology graduates who were seeking placements that would contribute toward the experience needed for entry into clinical training. This strategy resulted in high-calibre, motivated employees who were not concerned about the limited length of employment. High-quality supervision from a senior practitioner was made available, and the only drawback of the strategy was the inevitably high turnover.

Use of professional skills

Because the pilots forged new generic roles, some staff felt they had to let go of, or refashion, the clinical, professional and therapeutic roles they had invested in. Service managers told us that some could not do that, and left, while others initially felt very deskilled.

> Why do we need a new model? I'm a psychotherapist; I know about talking to people. Why are you telling me how to do an introduction? (M18)

Clinical leads found that those without a clinical background – uncertain expectations, and no model in mind or status to defend – tended to settle down quicker, and 'got it' (grasped the model) more quickly. It can be difficult to predict whether professionals want to maintain their particular skills and be called on to exercise them: or conversely joined the team to do something completely different (S60). Several services had to redefine roles: therapists have had to take on social- or advice-worker roles; unqualified people have taken on therapy. Some staff found that expectations for the work they would be doing were not met, causing resentment.

It is difficult then to consider the pilots as 'multi-disciplinary' in the established sense of the term. Despite the range of professions involved, most staff were recruited to deliver the service model, which may have had no precedent. A TC facilitator does not need to be of a particular professional background, although experience in TCs will be useful. Most services, including the TCs and group-based models, aimed to deliver a mix of psychotherapeutic and practical support. One team, advertising for staff wishing to acquire competence in psychotherapy, was inundated with applications: but few applicants wanted to also engage with the users' housing problems or need for dentures. Most of the services have demanded this degree of flexibility in attending to the hierarchy of service users' needs.

> This is a bigger role… it's in your job description, this is not sitting in the same room week after week you know, talking to the same person. This is being out there, doing the things that the individual needs, to be able to move forward in a therapeutic way. (M45)

Several members of front-line staff told us that working in pilot services had left them feelingly deskilled or demoted.

> There are six of us nurses working here. We [nurses] represent the highest in the one discipline in the service… I think we carry quite a lot and I have felt quite deskilled at times that I'm not at that sort of level of expertise where my opinion matters that much. (S62)

The demands of running multiple service components have meant that, at least in the early stages of service development, staff often had to take part in publicising the service. Some staff who had previously worked in psychotherapy services found tasks such as handing out leaflets and telling teams about the new PD service frustrating.

Team working

Team working – the sense of joint responsibility for service users and mutual support between staff – was very important to pilot services, even though there were rifts between some individuals and teams. Sharing the difficulties of working with particular service users and getting advice is hugely important and several teams have 'back-up' workers, who may or may not be known to service users. Handovers and post-group meetings are considered important means for sharing responsibility and containing staff anxieties. Team working and clear communication is also necessary to minimise 'splitting', the tendency among some people with PD to separate significant others by identifying them as either wholly good or wholly bad.

Where there are different functions within a single pilot, and different teams, there is a predictable potential for splitting, poor communication, divergence of aims, accusations that the other team take soft options and 'Chinese whispers' (M11). Several pilot services have considered how communication between staff teams could be improved. Ways of doing so include ensuring that at least some staff work across the different components of the service or swapping some staff between different components of the service.

Staff 'dysfunction' and supervision

There was widespread agreement that staff who have unresolved psychological issues were unlikely to be able to work productively with people with PD. Concerns were expressed that staff with such issues may even further damage people with PD. Service managers described problems associated with employing people who became increasingly demanding of support, and increasingly like service users. One manager speculated that health and social care services attract vulnerable people, and empathy with users may degenerate into need.

> Because our clients are so fragile, they don't deserve a therapist that's fragile. You [the therapist] can talk about anything that you have resolved or is not current. You can keep people at bay. (M33)

Clinical leads varied in how much weight they placed on the calibre of the staff member, and how much on the support that should be given to supporting staff to reinforce their resilience. One said:

> It is not our role to contain the problems of the therapists: we are here to work as professionals, not to be patients. (M45)

Another felt that – provided staff had the right qualities – it was reasonable to offer open-ended support because it would not be abused. A therapist from this team clarified:

> We believe that the needs of PD service users are likely to be compromised when anxiety in the professional system is high, in whatever setting they find themselves… we maintain that the work of actively engaging PD service users in their care and making change cannot proceed without a well-supported and experienced core group of professionals operating from a safe base. (S38)

Most of those teams who work psychodynamically hold the clients as a team, and inform them that information divulged will be shared throughout the team. This is vital to the containment of risk and anxiety, reduces the capacity for splitting, manipulation and inappropriate attachment, and also permits more creative thinking.

> New clients are informed of this policy: why it is so important that nobody is sitting in a corner with just their client and not sharing. And the client knows that as well – the therapists tell them that the information is shared with the unit, so there is a feeling of belonging. (S52)

Staff said that their own humanity was important to their interaction with service users and, from time to time, they should recognise their own vulnerability. 'Everybody is vulnerable to something at some point in their lives' (S61). Examples might be a staff member with bereavement issues deciding not to take a group on this issue on a significant anniversary. One TC nurse suggested that those who have had therapy as part of psychotherapy training may be fortunate: it teaches them to 'recognise their own buttons' (S61). As one manager commented, the problem with recruiting people who did not have this background has been the amount of time it has taken to get them to recognise and accept their own vulnerabilities:

> It is especially difficult to provide containment for people who don't realise they need containment. (M45)

In some services there are clear distinctions between those who have had therapy and those who have not: often they are running different aspects of the service.

Splitting within the teams – often along predictable fault lines between sub-teams with different functions – has been a tangible problem within most of the pilots. Service users may characteristically split staff into good and bad: or staff may do this themselves.

> It sometimes comes out in a weird direction, but it is always the same split: those who would overindulge the patient versus the unfeeling bastards. (M1)

Some of these splits reflect different ways of working: e.g. psychotherapeutically trained staff and those from more pragmatic, perhaps social-work backgrounds, may have different ideas about the type of discourse that the team should use in talking about the work. The latter may resent what appears to be prying into their own personal motivation. There may be splitting between the hub and spoke aspects of the team: those training staff in the wider arena may feel marginalised compared to those working directly with service users. Psychotherapy is also founded on a model of supervision that other professions may not subscribe to:

Psychotherapy can't work without supervision... you need to have the third eye, the learning and the observing you get or whatever you want to call it. You have to have that otherwise you just get caught up in something mad and you can't stand outside of it. So it's vital and I don't think you can do without it. (S61)

It was universally acknowledged that the client group was, and would continue to be, challenging. Some staff recognised the tendency for staff groups to 'mirror' the very splits and antagonisms shown by the client group. There were also acknowledged tendencies for service users to try to cross boundaries, e.g. between staff and users: and some examples were made known to us of cases where staff had entered into relationships with service users, gave their personal phone numbers to users, or otherwise acted in an unprofessional manner. In some respects, these incidents may arise from the desire to reduce discriminatory practice, to engage with service users as equals: but the balance between this and consistency of boundaries needs to be carefully monitored. Staff talked about the balance between being a real and honest person with service users, and giving them appropriate feedback on the effect of their behaviour on others, and the real need to maintain some level of humane detachment. Service leads told us that, while these problems are not confined to services for people with PD, the tendency for splitting and pushing the boundaries in professional behaviour are particularly clear in this context. It is not clear how any manager could rule out such misconduct before it happens, except through active measures to anticipate and reduce these occurrences.

I suppose the most challenging thing is the emotions that they bring out in you and how you manage those emotions and where you take them… Or people kind of wanting to make everything better and kind of rescue somebody when probably that's not helpful either… and for myself as well, sometimes not knowing what to do for the best really, what's going to be most helpful, feeling a bit stuck at times. (S63)

Most clinical leads thought supervision was extremely important, but there were a range of 'controversies' and difficulties which they highlighted. Staff of several pilots felt that external supervision by a person who is otherwise independent from the team is also important. Benefits of external supervision were seen as: enabling the team to examine their feelings without the restraints which might apply if a manager were present in a supervisory role; enabling the manager to participate and benefit equally; obtaining input from a person who was less likely to be drawn into the personalities of individual service users and staff members. It was also argued that team working and external supervision were important methods for avoiding staff burnout.

Several stated that both individual and group supervision were important, but limited time meant that both were seldom possible. Scheduling group supervision was made more difficult by part-time working; night shifts; the pressures of running a group programme; and in some instances working across very dispersed geographical areas. Some staff reported wanting supervision from a senior practitioner of their own professional background, which was not always possible. Some staff were also reported to be reluctant to share feelings in groups or expose their practice, particularly psychotherapeutic sessions, to the supervisor e.g. through the use of taped therapy sessions.

There were no service models in which staff did not have some criticisms of the way they were supervised. Administrative staff felt that they needed more training and supervision to work with this client group: they were likely to spend time with them, organising expense payments, etc, and could be subjected to difficult behaviour, including self-harm, theft of personal belongings and threats. Several pilot managers expressed interest in organisational audit (see Appendix 1) as a useful tool for their teams.

> It actually helps workers to survive in their work, if they have a place to think… one of the main theories about, you know, personality disordered people is that they don't have the capacity to reflect on themselves and so if [they are involved with] an organisation that equally can't reflect, you're going to have this sort of mirroring that goes all the way up from the client themselves all the way up through the organisation that's trying to help the client. (M21)

Pressures to increase caseloads reduced the amount of time available for reflection in several services, though service leads were keen to make sure that these pressures were resisted:

> There's always the pull to do more: in this kind of work, it's better to think more. (M19)

The rewards of working with people with PD

There were many comments about the satisfactions of working with this client group. Despite the boundary issues, staff felt that their difficulties were part of a continuum of the human condition: we can all relate to them, and we may also share the use of strategies for managing them. Most of the models used by pilot services utilised groups and peer support.

> What gets missed out of the account of people with PD is how sensitive, aware and supportive they can be: our role is to harness that. (M19)

Other positive aspects of working with people with PD were stated to be that work was never boring, and that people with PD were often caring of others, honest, supportive and creative. Work with users appeared to generate strong attachments and shared insights and vision.

Key messages – staffing issues

There is a high degree of consensus about personal qualities needed by people working in services for people with PD. Among these emotional maturity, acceptance of limitations, ability to work as a member of a team and a high degree of personal resilience were regularly mentioned.

Service managers highlighted the importance of personal attributes over professional backgrounds. Front-line staff, in most pilot services, are asked to combine psychological ways of working together with a willingness to help people solve practical / social problems they often encounter.

There are 'predictable' and insidious pitfalls for staff working in these contexts, and proactive – not just reactive – measures need to be in place. Although not all staff were comfortable with the prescription, it appeared that these measures are most likely to fulfil

4.1.6 Leadership and management

Management functions

Service managers and front-line staff highlighted a number of roles which they believed leaders of PD services needed to fulfil. These included:

- clinical supervision, including taking responsibility to permit new ways of working
- operational management
- carrying the vision, and enforcing it to prevent dilution
- being accountable, including bearing the brunt if things go wrong
- gate-keeping the service: all referrals are considered by some managers to ensure they meet criteria and can be safely contained
- containing workers, especially through personal consistency,,and a safe pair of hands
- disciplining workers who overstep boundaries
- promoting the interests of the pilot service to commissioners
- bringing back, repackaged where necessary, criticisms from outside from which service needs to learn
- championing, protecting and promoting the service in relation to external organisations.

Because quite often the staff just don't have the full knowledge… I sit on all the upper management committees across the Trust, and I know the bigger picture. I know the national picture. I know the Trust picture. I know what's tolerated and not tolerated and I know what will stand up in an untoward-incident report or a coroner's report. (M32)

Service leads stated that strong, confident and visionary leadership was needed to gain funding for and deliver the pilots. Containment of staff anxiety also requires strong leadership. Many of the pilot staff felt it was essential that a person in this role should have a clinical background: although there was clearly a real need for administrative and managerial skills, it was felt that clinical management and supervision was the more vital role.

Recruitment of managers

In some services, clinical and operational leadership has been provided by the clinician who led the initial proposal, generating consistency and vision, but perhaps some inflexibility. Elsewhere, recruitment into management posts has been more difficult. In some pilots, existing managers of other services were asked to take on this role and had to combine it with other major responsibilities. Staff in such services generally felt that their anxieties had not been well contained. We note that pilots with insufficient management time resulting from either late recruitment or managers having to combine these tasks with other management responsibilities have been slower to evolve into fully functional services. Front-line staff in several pilot services stated that PD services should be operationally managed by someone with a clinical background, implying that operational management must take into account the clinical needs of service users and staff.

> I don't think I'm being supervised in a management capacity by somebody who has more experience than I have… in most of the roles I've had I think my manager's had more experience in management, managing people and I've often missed that. (S62)

> I think it is extremely important for people in that position to have a clinical background, and to have worked with this type of person: managers in the NHS often haven't. Clinicians understand each other. (S35)

While some pilots had to share a manager with another service, others were effectively led by a partnership of two people loosely aligned to general and clinical management functions, and this was felt by both staff and the managers themselves to be hugely successful if they had good communication and trust. A prerequisite of a good partnership was the need to debate differences openly but privately, so that staff witnessed consensus: otherwise differences between managers could exacerbate 'splitting' within the service.

> If you have a clinical lead and team manager working together and having good communication, that's an ideal team. (M19)

Management style

The same managers were both criticised and applauded by different staff for their style of leadership. Most prominently, these were charismatic and autocratic: but some staff found them containing and reassuring. In general, it seemed that more confidence was placed in this type of leader than in less influential leaders: and these leaders have stayed with the service. There are clear parallels here between the client group and the staff group: both may respond well to consistent containment: authoritative but supportive, omniscient and all-knowing. Several managers described themselves as 'parenting'. Several service leads have a charismatic approach to managing their teams, which may be necessary if their 'parenting' functions are to be accepted by the team.

> I am the strong parent, I pull the team into line, I pull my clients into line… I consider their needs, I have a huge amount of compassion for my staff and my belief is that I look after my staff and then they look after the clients. But with the clients being so chaotic and that I'm expecting them to work is so demanding, something's got to be solid, and that's me. (M33)

There is a tendency for leaders to attempt to quell dissent by taking a firm, unequivocal stand. Service leads told us that this could help prevent splitting. For example, in one service, a single middle manager was given total authority to decide who could use a resource highly valued by service users: this avoided the possibility of people trying to manipulate other staff members to concede use of it. Several managers said that, having consulted their staff, they insisted on having the final say in decisions: where consensus was unlikely, there was a need for a decision and further discussion appeared wasteful.

> We don't have time to try out every idea… because most people are used to working in psychiatry or psychotherapy very independently: there is a hierarchy, but a distant hierarchy. Here we need much tighter control and sharing of information. We need clear boundaries, clear aims and clear messages. I find the same with therapists as with patients: they need clear control, clear containment, clear messages. We don't have time to debate. (M45)

The lack of an authoritative and containing leader can keep the tension for supremacy alive, particularly where there are dissenting models and teams.

> I think our hierarchical and management lack of structure is really clear sometimes when they get us all together in a meeting that actually we're not sure who's in charge or who should be doing what. (S62)

Managers tended not to resent challenge: what they did object to was dissent being conveyed between staff in clandestine ways, rather than overtly. However, most of those leaders who were happy to be challenged retained the determination to preserve and implement their own vision. Charismatic and visionary leadership can become burdensome and disempowering. This approach also raises issues about sustainability of the service if the service lead leaves. However, questioned about this, pilot staff and managers said they could now carry the service forward.

Hierarchy and democracy

Many of the pilots perceive themselves as 'flat hierarchies', by which they mean that there are few hierarchical distinctions, implying that power and accountability and personal weight are relatively evenly spread. However, these are relative concepts. Within the pilots, there are examples of levels of middle management creating rifts, with different functional 'teams' headed by different figureheads for staff to take grievances to. This would appear to be one reason why a service with a relatively 'autocratic' leadership with a single figurehead or arbiter is less commonly split. Even in TCs, which place a particular importance on democracy, staff may feel that responsibilities are more readily shared than rights.

> [The consultant] said to me, 'we're all in this together, we're all in a flattened hierarchy, it is down to you, you can do that' but then I think 'hang on here, really I'm an E grade nurse, why should I have to do all this when other people are being paid thousands more than me, maybe it's more their role'… but I suppose that's just something that I have to sort out myself. Because although we're all equal, not so far as salaries. (S64)

Security is understated: where transgressions are uncovered, they are brought out into the open. In one service, tranquillisers were being sold among clients. An amnesty was offered to uncover the extent of the dealing so that people could discuss the ramifications and how to deal with them.

The TC projects and the service user network show varying levels of reliance on users to make decisions about the service, as this can hardly be imposed but should develop as the culture does. One puts every decision to a user vote; another will ensure that staff never outnumber users on any given day. Getting the informed majority view from users definitely slows up decision making, and can provoke major anxiety among service users. There were issues among staff and users about how much democracy should be offered, and how differences would be accommodated. The principle in some user-led services seemed to be: 'where there's been no discussion, nothing will happen' (S17). Similarly, if no agreement or compromise could be reached, nothing could change. The desire to involve service users in *all* decisions requires active measures to resist 'natural' tendencies to exclude them from some decisions or knowledge. Paternalistic decisions about what they should / shouldn't be involved in are not then appropriate, although they may be practised by managers in relation to staff as a means of containing anxiety.

Some staff felt that service users have all the rights and staff have no say. One service manager felt that it was disingenuous to offer openness to clients unless you had similar relations with staff.

> [The managers] don't necessarily contain all the issues and anxieties, you come out with them and say, 'I made a mistake, can you help me find a way round that?' People don't normally do that in management, they don't really own up to that. (M19)

In many of our pilots, driving forward the service, and complying with the vision already laid down in the original bid, placed great limits on democracy within staff teams: at some point, discussion had to be shut down and a plan implemented. What are the desirable limits of democracy in staff teams; among service users?

Key messages – management and leadership

Like service users, front-line staff working with people with PD also need containment and consistency. Service leads and clinical managers play a key part in providing this.

Front-line staff value managers who have a strong clinical background and can combine operational management with clinical supervision. Where this is not possible, clinical and management functions can be split between two senior team members, provided they have clear communication and present a united front.

Charismatic and autocratic leadership style were evident among many service leads. While this approach provides the strong leadership that such services may require, it places a burden on service leads and may affect the sustainability of the service when they leave.

4.1.7 Involvement of service users and carers

There are a large number of ways in which service users can add value to PD services, not all of which can be fully described here. Examples from the pilot services include:

- in designing the service specification, and reviewing and auditing the work

- in running therapeutic communities and user networks

- in crisis management and out-of-hours support

- in understanding and managing their own therapy, goals and outcomes

- in critiquing and reviewing services

- in recruiting staff

- as employees of the service, whether paid or voluntary.

Involving service users in service development

Among the pilots, services that intrinsically rely on peer groups such as TCs have felt confident of their ability to work closely with service users; those with some group structures have found a clear basis for association and feedback; while those who work primarily with individuals have had the greatest difficulty in capturing user feedback. The latter services report that clearer methods for involving users have emerged as group-based interventions have developed as part of the services they deliver.

User involvement (UI) was a particular challenge for new services. In the initial stages of developing a service, there was no clear means of involving 'prospective' clients. Several services therefore 'borrowed' experts by experience (XBX) from other services to act in a training and advisory capacity. This was particularly important to services planning to 'import' a TC model. One pilot organised a local stakeholder event and used the cohort of service users from the first group to advise and support the next cohort in the network. Pilots invited service users from national organisations, from other specialist services and from their own contacts to help design the service and / or carry in the culture. Some pilots have invited the voluntary sector, e.g. Mind, to work alongside them to develop UI, but this may have the disadvantage of making involvement an add-on.

However, some providers have concluded that there is a particular difficulty in canvassing the views of service users new to a PD service about what they think, or that service users may then feel that providers are unprofessional, and do not know what is best for them. Service users may also be less interested in expending time on issues of service design than on their own personal and treatment agendas. An ex-user commented:

> It's an absolute nightmare, it is, absolutely… because people are apathetic. Service users are that much more apathetic and people diagnosed with PD are doubly apathetic, and I can say that, because I am. I set one up in our inpatient hospital and that was easy because they are there, they're bored, stupid and need something else to do. (S28)

A further cost of high levels of service-user involvement is the amount of time that is required. One pilot was committed to sharing all policy decision making with service users, including the details of negotiations with Trusts. However, staff reported that users were often not interested in this detail. One manager stated that sharing information about negotiations with the local Trust had left service users and staff feeling less contained.

Delivery of services by service users

The ultimate commitment to service-user involvement is to train users to replace staff, e.g. to take over group facilitation. While a minority of pilot services aspired to this model, none had implemented the approach during the period of this study. One service had started to train volunteer service users, but faced a series of obstacles including the impact on benefits and the need to have flexible work patterns in case service users fell ill. This meant that users were being temporarily assigned unpaid 'bank' work while more formal arrangements were being developed.

Therapeutic communities also rely heavily on service user input. It is possible for meetings to involve little or no verbal interjection by staff. User-led models need clarity about purposes, relationships and accountability, and governance, risk management and confidentiality. In some pilots, user-led groups were seen as a step-down intervention, where graduate users could develop skills and confidence and support each other after detachment from the service proper. Experienced service users are used in some of the TC pilots to guide people into more intensive services, and could also play a role in supporting people on waiting lists. Service users can then expand a service's capacity.

It is also important to such models that members sign up to and enforce the disciplinary aspects of the service. It is a source of satisfaction to staff that members own and implement much of the activity of the group.

> Now the members know that if anybody comes along to the group saying, 'I've overdosed,' or, 'I'm going to do this,' then it's… 'okay we need to stop the group here and we need to get the risk protocol and we need to go through this'. (S20)

Staff reported that service users have sometimes been able to iron out ambiguities in procedures that staff had failed to spot.

Employment of service users

At least four of the pilot services employed people who were explicitly service users. There are boundary issues, and it is generally accepted that one cannot be both a user and provider of a service. This precept is close to the assertion made by managers that they are not there to offer therapy to staff (see Section 4.1.5). A time lapse between use of, and working within, the service may be sufficient to implement the boundary: one service makes the proviso that employment in the service disqualifies the person from being a service user ever again. These provisions must provoke some reflection about the reality of a person's recovery and their future resilience.

If service user employment is to become a reality the provision of training appears crucial. Staff report that it has been time-consuming to draw up contracts according to Trust policies. There are some differences in the terms of employment for these service users: for example, they may not be covered for sick leave. In one service, there is commitment that all interested service users can undergo the training offered for these posts so as to ensure equal opportunities, although they will be interviewed in the normal way before recruitment. One service lead suggested that employing a service user may be more difficult for the staff than it is for the service user themselves. One employed service user suggests there are advantages:

I class myself as a service user who now has a job, and I don't actually identify as a client because it's not appropriate, but I think it gives me a slight advantage in that I know the system and I know how it works and also doesn't work… I know what it's like to have a diagnosis, I know the system, and I know what a lot of tosh it is to assume it's so-called untreatable, and I know professionals' attitudes. (S28)

There is some acknowledged tension between service user-initiated groups and professional-led groups. One group with no staff input has been given permission to use the Trust and PD service logo, but in recommending it to vulnerable service users, the Trust cannot take responsibility for outcomes:

Because it's got the PD network logo on and it's run by service users I feel uncomfortable. (S67)

Accountability then remains an issue where service users work autonomously.

Services for carers

Few of the pilots have so far succeeded in delivering services to carers. While one pilot has managed to set up regular groups which combine psycho-educational and peer support, another had been unsuccessful in its attempt to set up a similarly organised forum. One service lead reported that working with carers was challenging because service users and their carers may have conflicting interests, particularly around the use of existing services. Too often, it was felt, the main demand of carers was that people with PD should use a service that the potential service user did not want.

At the pilot site where a psycho-educational and support group has been set up, staff felt that the term 'carer' may not be appropriate in this context. People with PD may provide support and care for others and value the support and care provided to them, but unmet dependency needs in the lives of some people with PD mean that long-term relationships based on receipt of care may be counter-productive. While the term 'carer' has been extensively used in the context of physical illnesses and those with psychosis, it was felt that in relation to people with PD, the term 'friends and relatives' may be more appropriate.

Staff at several pilots stated that they wanted to develop something for carers, but that this had not been a service priority. However, they felt there was a need for:

Some carer training on boundaries, how to manage and how to live with someone who's presenting difficult borderline type stuff or whatever, how to handle self-harm, how to manage. (S67)

Key messages – user and carer involvement

High levels of service user involvement are integral to some service models. Service models using associative methods, such as groups, may find it easier to develop involvement than those delivering one-to-one interventions.

Involving service users in service development is seen as beneficial for the service and potentially therapeutic for service users – as a means of supporting efforts to reduce low self-esteem and increase their sense of agency.

Service users with PD can be responsive, creative and supportive, and may go on to become full employees of care services. However, all levels of involvement require boundaries and safeguards.

Competing demands during the first phase of the development of these services mean that few have implemented systems for working with and supporting friends and family of people with PD.

4.1.8 Working with other local services

Means of engagement with local services

Pilot services have engaged with local health, social care and other frontline services in a number of ways. This account deals with some of the common themes arising from these encounters from the perspective of the pilot staff. Pilot services worked with other local services to:

- Promote and publicise their service: through attending team meetings and supplying literature.

- Establish good working relationships: through development of shared protocols, e.g. with crisis services, memoranda of understanding, and harmonising areas of practice such as risk management.

- Provide opportunities for learning about PD: through offering basic awareness, participatory training, more advanced / accredited training, individual and team supervision, work and training placements and staff secondments.

- Assess people with complex problems in order to determine the nature their problems, develop formulations and treatment plans.

- Co-work cases with existing key workers or take people on for direct service provision.

- Contract out aspects of their work, e.g. to the voluntary sector.

The range of services with which pilots engaged was broad. As well as community mental health teams, some pilots worked with primary care teams, housing and benefit agencies, and organisations as diverse as the police and the Samaritans. Some of these contacts were at the suggestion of service users who had found the service that they received wanting.

All of the bids for pilot monies involved consortia or networks of local services. Although all have relationships with local mental health services, at the very least by referral, a minority of the services have utilised resources from other statutory and voluntary-sector agencies, in some cases taking on part-seconded staff. This has exposed some of the limits of joint working. For example, where probation staff have been seconded, the reciprocal sharing of information has been useful in individual cases, and educational in general, but has not overcome the exclusion of mentally disordered offenders from the PD service. It has clearly been difficult for frontline services to share / second staff members, and requests for increased hours have been refused. In other areas where there is a shortage of qualified staff, the new services have recruited voluntary-sector staff, which ultimately reduces choice for service users. Some of the Networks have contracted-out aspects of their brief to voluntary-sector partners, but may be planning to renegotiate or revoke such arrangements because the agendas of such agencies do not necessarily support their own strategic development.

Several pilot services offer case consultation with staff, away from the patient.

> There needs to be a space to think about that without the patient being there… It also gives the care coordinators the freedom to talk about how the patient is impacting on them. One of the problems I have identified in supervising staff is they say, 'I've been really professional, I never show my feelings…' it's as though they mustn't have feelings. But we're saying, you are allowed them, they're your tools. If you don't allow yourself to have them, you will act on them in a different way or space. (M8)

The management and support of people who self-harm was one area where pilot services thought they did have much to offer other mental health services. Some services were particularly keen to work with inpatient staff, as service users who self-harmed often ended up on wards, to the discomfort of both staff and patients. A challenge here was the inconsistency in ward staffing across shifts and locations.

The scope for indirect service provision

The balance of direct and indirect service provision across the pilots was driven by different factors. Many providers referred to their commitment to hard-pressed local statutory services: but the more clients they took into their care, to the relief of local services, the faster they reached the point of full capacity. Some of the pilots were actively engaged in seeking ways they could continue to deliver something of value to statutory providers once this point was reached. Others felt that the delivery of training and consultation to statutory providers was more likely to deliver sustainable benefits to service users than the taking over of direct care. Some pilots were hard-pressed to deliver direct services across a wide catchment: there was little time left to deliver indirect ones. Another service relied heavily on the commitment of its lead clinicians to deliver training initiatives effectively out of hours. Several services engaged designated staff members to promote awareness and deliver training. This latter approach was not entirely successful, as these staff reported difficulty in maintaining credibility with their audiences unless they could demonstrate experience in direct working. Credibility may not be enough without other incentives, such as taking on the management of difficult people.

> One of the learning points is here: if you see patients [for the staff], the staff will be open to training and liaison, so it's an opportunity. I tried to train people before, but they weren't interested: having the patient resource has opened them up. (M45)

Pilot services almost all stress the importance of team support and containment in explaining how they work with clients: whether directly stated or not, the comparisons are likely to become clear. One of the pilots was particularly concerned with supporting provider teams to explore their own issues and needs.

> The culture of CMHTs pushes staff to see a lot of people and move them on quickly: really important to have space for reflection, to 'stop and think'. You need to be prepared to work with a person for a long time, and to relax with that. (S10)

There was a sense from the majority of pilots that they want to ensure that they offer as many service users and staff as possible some benefit which will at least keep them in contact with the PD service.

> There are simple things you can do, very low level interventions. You can explain to the staff why they behave as they do, you can tell them about PD. There's nothing else around here: that's the horrid bit. (M1)

Other strategies may include the offer of additional support, if and when a place arises, or if and when the client has overcome a particular hurdle. There is a 'danger' that such accommodating services will overstretch themselves.

> The ambition within the team to deliver different things along with the demands of complex needs and new service and the bureaucracy required by Trust may have led to unsustainable workloads. (S6)

Support to individuals and teams by pilot services may have large benefits for individuals, the system and financial savings. In some cases, direct or indirect supervision, or the offer of a place to a client, has enabled people with long experience of confinement on hospital wards to be discharged to community settings, rather than referred on to more secure settings. The cost savings in individual cases can be very large. Pilot staff suggested that their 'indirect' supervision of service providers had some advantages over direct service provision. It could:

- Contain anxiety of frontline workers in relation to risky service users.

- Raise awareness and confidence in these workers.

- Transfer skills in how to manage people with PD.

- Support people with PD – many of whom had attachment problems – to remain in valued relationships.

- Support the premise that PD sufferers should not be artificially excluded from MH services.

- Provide a more cost-effective and accessible service, than direct provision, in areas of low population density.

- Reduce costs where people with PD are high service-users.

Engagement with local Mental Health Trusts

Developing and maintaining support from, and collaboration with, local mainstream services has been important to the security of pilots and particularly to the managers who have acted as liaison. It was part of the early experience of several pilots to feel disparaged by seniors, from whom general attitudes flowed, and they have worked to find diverse ways to be useful and supportive. Some workers, for example, have wanted to keep their PD clients, so services offer consultation and joint working options as an alternative to taking over client care. Because of the 'fire-fighting' ethos of CMHTs, where there is little space for reflection, there have been resentments about the apparent ability of pilots to 'select' clients; to refuse to take on CPA roles or other statutory responsibilities, and to spend time deliberating and reflecting.

A new service being developed for people with personality disorder is enormously provocative to mainstream services, you know. You can say, 'this group of people have been marginalised and they've not been provided with the services that they should have had,' all you like but you mustn't forget the impact that they [clients] have on those mainstream services. (M19)

In the beginning, the neighbouring Trusts viewed us with hostility and envy: I was fighting for boundaries, money, services; some people saw their own images as compromised. It was a very vulnerable time for me, for the unit… that was a big, big problem at the beginning. After a year, I have come back into the circle, and all this has changed. But all this has made me a stronger, wiser politician: people respond better to you when you are stronger. (M45)

The reduction in workloads when Trust patients engage with a PD service may be delayed. One member of staff was told by a referrer:

You know I hated you for distressing my client who has been hard work for the last eight years… but then all of a sudden I've been able to reduce [contact] to six weeks. (S50)

One service referred to particular difficulties in the reorganisation of its host Trust: having 'convinced' one set of managers about the viability, usefulness and risk management of the service, they were all replaced and the task began again.

In most cases service leads told us relationships with host Trusts have improved over the life of the pilots as mutual understanding has developed.

We need to fit in with the Trust clinical governance and the risk management processes, and that is what we will do, but… it's a two-way process, we need to help educate the trust and the clinical governance processes about why the service is different, and why it needs to be different, and why we're being creative, and perhaps a different way of approaching things. (M59)

Key areas identified as contrasting with traditional Trust practice have been the different models of risk management, particularly in relation to self-harming, and the emphasis placed on valuing and trusting users to design and deliver therapeutic services.

Other issues

Promoting the new service with the right balance of expertise and uncertainty or humility has been challenging. It was difficult to promote the setting up of a specialist service without implying that existing services had somehow failed this client group.

It is important to not locate 'blame' in either the patient or the worker [who may naturally feel her / himself to be the brunt of criticism]. (S30)

And it's a double-edged sword: they want to refer to you, but success is resented: you have to work with that. (M19)

Managing the expectations of staff in local mainstream services has also been difficult. Some mental health services had hoped that the pilot service would take on their existing clients. Several pilots targeted those not engaged in services, including one that only took self-referrals: local CMHTs didn't necessarily understand or sympathise with this emphasis, as they have not experienced a reduction in their workload resulting from the advent of the new PD services.

There is some disquiet among local services, reported by pilot staff, about the failure of services to take the most risky clients, particularly if risk is felt to be to other people. This is an issue closely related to the paucity of services for people with violent and / or offending services in the community, and so disappointment expressed by local stakeholders cannot fairly be seen as the responsibility of pilots, and may reflect the disproportionate emphasis in mainstream services on people with antisocial PD. Another criticism from mainstream services was that some pilot services were not taking clients with other mental health problems.

Key messages – working with providers of other services

There are a number of ways in which pilot services can and do work with local services. All pilots have recognised the importance of promoting innovative ways of working with people with personality disorder among the range of service providers.

Disaggregating direct from indirect work may reduce credibility of the latter. Staff may have more confidence in personality disorder workers whom they see actively working with clients: practice speaks louder than theory.

Especially when a model is new, it can take a lot of time for local providers, especially those with statutory responsibilities and regulation, to overcome misconceptions and learn how the service can help them.

Engagement with local services, and the offer of training and support, has required tact. Hard-pressed mainstream mental health services may feel blamed for not having provided an adequate service. Pilots have found that acknowledging the impact of this work on care teams, and providing space for them to reflect on that, has helped to overcome resentment. The implication here is that mainstream staff do not routinely have such opportunities.

4.1.9 Issues in setting up and running new services

Many of the factors that service providers discussed when describing their experiences of organising and delivering these services were not about personality disorder per se, but about the challenges of setting up a new service and the impact that 'pilot' status and funding arrangements had on the way that the service was managed. Some have been referred to in previous sections, others are described below.

Pace of development and expectations of the service

Several pilots were unable to get up and running as quickly as had been hoped. The slow start affected recruitment of suitable staff and staff morale, and created slippage in the budget. The way that the pilots were funded meant they had to recoup money from the host organisation. In some instances this created uncertainty about the time and resources that were available. This in turn impinged on the ability to plan recruitment of staff and the management of other resources.

Some staff reported that time schedules for setting up services were optimistic and in some instances may have been unrealistic. This was especially true in those pilots where the amount of management time available in the first year was limited. Some staff told us that setting up, steering and supervision of innovative services with challenging clientele needed more management time than was available. Some pilots had a part-time service lead who had responsibilities for other services. Setting up the pilot service very often put a huge burden on lead people. This was especially true of those pilots that had set out to provide a range of different services and made commitments to support and train staff at other services.

> We were lucky, we were a tiny little team and we had a very clear plan of action and we just implemented it… we didn't say we'd do more than what I thought we could do with £300,000. I think if you have £1 million, then you have to agree to do everything under the sun. (M32)

These challenges were compounded in pilots that had to develop services over a wide geographical area. Replicating services at a number of different sites was inevitably time consuming and needed more complicated systems for managing services and supervising staff. In one instance, staff reported that this led to problems around ownership, with unequal participation in further development of the service.

Service leads told us that uncertainties about long-term funding made it more difficult to manage the service. Pilots were told that they would be funded centrally for their first two years, after which recurrent funding would need to be negotiated with local Primary Care Trusts. This meant that managers did not know how long the service would be funded for. Almost all pilot services found this difficult, not least because most were committed to a service model that anticipated long-term contact with patients. Most services were also committed to being open with clients about what they could expect, not least because many had experiences of being let down by services in the past. However, talking to service users, about uncertainty over future funding and the possibility that services might be closed, created anxieties and was not necessarily therapeutic.

Finding suitable premises

Some service managers were concerned that if pilot services were based on established hospital or CMHT sites users would associate them with unsatisfactory or traumatic experiences of previous contact with services. For instance, the premises offered to one of the pilot services were located between a children's dentistry service and the ECT suite. Independent settings were generally preferred as it was felt they would facilitate engagement and would be less stigmatising. However, such premises were often not available, and in some instances service leads had to spend a large amount of time identifying suitable premises. The potentially temporary status of the pilots also led some to difficulty in competing for appropriate sites.

The use of voluntary sector or community venues raised issues for staff travel and security. One pilot, determined to establish a base away from mental health services, had a long battle to get planning permission in a residential area. Those that were situated in existing mental health units sometimes faced the challenge of how to mark out separate territories.

Staffing and staff training

Almost all of the pilots reported difficulties in sustaining staff morale and confidence during the set-up period, and this period was in many cases much longer than had been anticipated. Team building was necessary to raise morale and promote mutual support. Staff training was a huge task in the first year of most pilot services, and especially in those whose founders were developing an innovative way of working. Many services employed diverse people for their personal qualities, so there was no shared value system.

> I thought I could delegate at the beginning, but I couldn't… you couldn't ask them to take too much responsibility: even to learn new things really… and the constraints we have on time – the huge constraints from DoH – we don't have time to debate, or to have our own problems, except for some discussion in the team. (M45)

Establishing new ways of working within a limited timeframe.

Pilot services that focused on providing group-based interventions and were not based on the expansion of an existing service struggled in the first few months to build up a large enough cohort of service users to support the development of a group culture that could sustain this way of working. This was especially true of therapeutic communities. Service leads told us that TCs take time to 'mature', especially when there is no 'neighbour' from whom to import the culture. Policies can be imported, but must be tested and agreed to. Such services do not function well as a TC until there are sufficient numbers of people to generate interaction and peer support.

> They had that very powerful experience of authority being misused and their first experience of the therapeutic community is of the staff being warders, or screws, who were out to get them, when in fact the staff are bending over to help them. That has to be worked through. (M38)

With previous negative experience of services, and difficulty in forming trusting relationships, pilot staff felt they had to win clients over, and offer a level of consistency which was at times wearing. On the other hand, it was reported that having the capacity to innovate, to experiment, to try things, rather than be tied to ways of doing, or strategic 'must haves', has been a real benefit for pilot services, although at times they have had to fight their way through established clinical governance arrangements.

Flexibility has been a key value of pilot services. Working in new ways was challenging, and staff felt uncertain. Several staff admitted there were times when they did not know what to do, but many felt that their own practice, and the model for the service, stood to develop most when 'something comes up and you don't know what to do' (M38).

> The greatest revelation for me is that I don't have to have all the answers myself, or go and find them: but yet they can be found. Not necessarily that day or hour: but something will come up. We learn through the difficult times… and it's been terribly important to change our minds about things… there's always the pull to do more: but in this kind of work, it's better to think more. (M19)

Evaluation and inspection

From the outset, each pilot was required to evaluate the service they provided. Some services involved external groups and devised formal methods for collecting qualitative and quantitative data. In addition to this the Department of Health conducted regular reviews which involved meetings with service personnel and organised site visits by service user commissioners. These reviews, together with visits by researchers from the team involved in the project reported here, meant that pilot services were involved in multiple evaluations and inspections. Service leads at pilot sites reported that these placed additional burdens on them and some told us that they felt they were being over-evaluated.

Key messages – setting up new services

Many of the challenges faced by staff in these services were generic and reflected the demands of setting up a new service. Others reflected the 'pilot' status of services which involved a complex funding process and involvement in a variety of research and evaluation processes.

Other challenges were particularly pertinent to *personality disorder* services. Because there are no established ways of working, clients needed certainty and consistency and perhaps a long period of attachment, and interventions that involved groups and peer-support needed time to develop.

4.2 Referrers and commissioners

4.2.1 Referrers

At least two referrers from each pilot service were interviewed (see Table 2), except for the service user network, which only accepted self-referrals. Where there were different arms to the pilot, attempts were made to interview at least one referrer for each arm. The survey sample achieved range and diversity in terms of the referrers' professions: CPNs, social workers, psychiatrists, psychologists, GPs, and team affiliations: CMHTs, crisis resolution and home-treatment teams, a day hospital, a drug and alcohol team, primary care liaison team, a probation service and a non-statutory sector community services team for people with complex needs.

Referring service users into the PD services

Respondents had referred between two and 30 service users to the services (mean=7). Two people interviewed were service managers who had not referred people directly, but had managed a number of people who had. One respondent working in probation had not made any referrals. Reasons cited for low referral rates were lack of awareness, uncertainty about the new service and differences in service culture.

Referrers linked with six services mentioned that they would have referred more people, but that service users were either not ready for that level of service, or did not want to be referred. Referrers told us that some people with PD were too chaotic to decide whether or not they could use the service and others felt anxious about what this would entail. One referrer mentioned that they screened people before referring, as they had had previous experience of people 'not being [of] sufficient priority' (R22). Another talked about the same service, saying she had experienced a number of rejections of referrals before assessment. On the other hand a further referrer mentioned being pleasantly surprised at the range of people that were taken on, e.g. people with alcohol and drug problems.

A primary objective for referring service users into the pilot services was that referrers perceived that existing mental health services were often not equipped to help people with PD. They felt that the PD services could provide the containment, specialist skills, time, intensity of service and approach that mainstream mental health services were unable to deliver. Those referring into the young persons' service valued the fact that these service users would avoid entering mainstream secondary mental health services. For the vocational support service, referrers talked of wanting to help people feel more socially included through accessing work and education. Referrers to two services talked about trying to reduce unhelpful use of services for the service user, such as admission to mental health units or A&E visits.

Most referrers had a good understanding of what the services were trying to achieve, whether that was in terms of outcomes, such as reduced distress, or unhelpful service use, or in terms of the service model. Several mentioned the value of having written material about the service, or having had presentations from the service, in increasing their understanding.

The majority of referrers were fairly happy with the inclusion and exclusion criteria the services used. Where frustrations were voiced they related to the exclusion of service users who were too chaotic, not able to work psychologically or who presented with drug and alcohol problems or ASPD and offending behaviour. Referrers told us that, rather than being excluded on the basis of formal criteria, many of those who were too chaotic to make use of services were effectively excluded because they were unable to make the commitment required to engage in treatment. Although this was a frustration for referrers, they appreciated that if such people were taken on this could have a negative impact on the service received by existing service users. Several referrers expressed concerns that if a person with problems related to PD was not taken on by the pilot service there were no other options for them.

One referrer described a negative experience in which a person they referred, to a day TC, was subsequently excluded from the service for behavioural problems and not allowed to rejoin:

> So we had this community meeting and there was kind of my client and myself, it felt a little bit like we were in a courtroom, um, well the inevitable happened obviously the community who know… some of them didn't even know her, but obviously some who knew her kind of said well we don't want her back here because her behaviours are more challenging than we can cope with. (R21)

Referrer's views of assessment and treatment

One of the strongest themes that arose when discussing the experience of assessment and treatment was the importance of good communication from the PD pilot services. Referrers relating to seven services talked positively about the extent, frequency and quality of feedback and general communication about assessment and treatment. Referrers to two services talked about a problem of poor communication, and one in particular highlighted the problems in terms of risk and containment that can arise when communication fails.

> Then when they've taken them on we don't always hear about really important things that are going on for that person… that can be a worry because it can be about self-harm, or really important life events coming up, and so on, and of course these patients take great delight in exposing your ignorance. So it can be really undermining to find that one half of the service knows something that the other half don't. (R11)

The majority of referrers made reference to the assessment as an important part of the process, and some stated that having an assessment was one of the reasons for referring someone to the service. Referrers linked to two services made specific comment of how much they valued the provision of a comprehensive assessment, even if the service user was not taken on. Benefits included helping the referrer to develop their own management plan or to better understand the service user's problems and building confidence and trust for the service user. The nature of assessment varied widely between services, and this was reflected by the referrers, one stating that the assessment from the non-statutory service was a holistic, non-psychiatric assessment. Referrers for three services mentioned that the time taken to conduct an assessment was too long. In the case of a crisis-resolution team this was a particular issue as their timeframes for referring service users on was very tight.

> We have a problem getting referrals assessed by them. It's the speed, because… our timing is crucial to make sure that we've got a throughput because it's very quick turnover. (R15)

Some made particular mention of the skills of the service and their way of working. This ranged from valuing the effectiveness of engaging with service users and validating their experiences, trusting the service to be able to cope with challenging problems, through to commenting on the importance of combining group and individual therapy. More negative experiences of the process included one example where the referrer felt the service had promised their service user a number of aspects of a service which were then taken away. Another felt that the service was perhaps pushing service users too quickly to give up certain coping mechanisms and supports, such as medication and contact with their existing team.

Perspective on working with the PD Services

Referrers for ten of the services had carried out some degree of joint working with their local service, ranging from formal CPA meetings to staying in close contact less formally. Of those that had not undertaken joint working, the reasons cited included concerns about 'splitting' when more than one team was involved, limited time to continue to work with service users once referred, and the timescale of work – in the case of crisis-team members. Where there was joint working this was mostly seen as successful, though complex and challenging to get right. Good communication, having a clear and respectful idea of what each party's responsibility was, having clear boundaries, transparency of working, having a joint care plan, sharing a therapeutic framework and geographical proximity were mentioned as important in managing risk and avoiding splitting of teams.

Several referrers had had more difficult experiences with joint working. One, from a home treatment team, found they were working jointly due to crises rather than in a planned way. She felt this was due to the service working in office hours only and not being obliged to hold as much risk. Issues also arose around decisions about which team would retain care coordination where PD services took this on. Another referrer mentioned the problem of the PD service wanting the referring team to retain care coordination when the service user was no longer engaged with the CMHT. In another area the PD service 'insisted' (R24) on taking on care coordination and the referrer reported that the service user reacted very badly. The situation was reviewed and she was allowed to keep her care coordinator in the CMHT.

Referrers relating to six services felt there was a significant reduction in workload both for them and for other services such as A&E and inpatient services. This was especially felt to be true when care coordination was taken over and the actual caseload was reduced. Even when the numbers of service users was small, the impact could still be significant if the individuals referred required intensive input and had complex case-management needs.

Referrers to two services felt that their workloads had increased, though this was thought to be in a productive way. One was providing more psychological therapies to service users, which he felt was a result of the PD service raising awareness of what to expect. Another was of a voluntary-sector service who were receiving more referrals, since the opening of the service, of people who were not yet ready for the PD service. They felt, however, that as they now had somewhere to refer for longer-term support, throughput was greater and so it was worthwhile. One, however, felt that their crisis team had to manage the difficult cases that the PD service could not contain.

All the referrers who commented on the potential impact of the closure of their local PD services felt strongly that it would be a great loss to them and local service users. Some felt that closure would be a waste of the effort taken in setting services up, would exacerbate loss and rejection issues for service users and reinforce their historical exclusion from services.

Indirect service provision

Referrers linked to six services had directly received training or supervision from the local PD service. All spoke very positively about their experiences and described gains such as greater understanding of PD, developing skills in validation, being more aware of emotions that could be provoked by working with these service users, and providing better focus for their work with people with PD.

> It gave me that sort of added permission to back off a bit. I felt I was getting in knee deep with this client and I realised that it was doing her more harm than good by doing that. (R6)

With the exception of the consultant psychiatrists we interviewed, all those who had not received training expressed an interest in doing so. One referrer felt that training worked well, but that ongoing consultation was too demanding of her time, and was not effective on an ad hoc basis. One referrer who had been very positive about supervision did think that while she benefited from increasing her learning, the service users may be better served by seeing the specialist directly rather than her under supervision. Others talked about the benefits of more generic awareness raising such as leaflets and presenting to teams. One felt that these activities were vital in getting support from local teams. One referrer felt that PD services should have a stronger role in raising awareness and reducing stigma more systematically.

Outcomes

Referrers for eight of the services spoke about the importance of outcomes. The main outcomes which people spoke of were reductions in use of other services such as Emergency Departments, inpatient beds and outpatient appointments. Two mentioned the cost-effectiveness of achieving these outcomes. Others spoke of the importance of social inclusion either as developed by social networks encouraged by the service, e.g. in a community, or through direct vocational support provided. Some mentioned specific psychological changes which were important outcomes such as 'learning the capacity for feeling' (R14), 'sense of understanding themselves and being able to be who they are' (R9). Outcomes that were perhaps less easily measurable, but felt to be highly important, were service user satisfaction, quality of life and long-term hope.

Several spoke of the importance of thinking in the long-term about outcomes: the chronic nature of the problems of this group of service users suggested that two or more years in therapy might be needed to achieve significant change. They were aware, therefore, that changes may not yet be evident in people they had referred. Referrers also spoke of the need to look at how people were functioning *after* leaving the service as this may be the test of success.

Capacity, coverage and staffing

Of the 12 referrers who mentioned waiting times, five were very pleased with the speed of response, particularly in comparison to waiting times for psychological services. Six felt disappointed by waiting times and limited capacity, and some expressed the specific difficulty of raised expectations when a service became available, only to have it closed off to them as it reached capacity. However one referrer felt that, had there been a longer waiting list, some of the people he referred may have had time to be more ready for the therapeutic community that they were entering, with better engagement and outcomes as a consequence.

Several referrers described gaps in the services delivered by the pilots. Most of these were specific to the local service but more general issues included;

- Where there was no preparatory groups, the transition from mainstream mental health to an intensive service was often thought to be too challenging.

- Gaps remained for particular sub-groups which services would not work with and who were left to 'bounce around the system'. Notable among these were the chaotic, those not 'psychologically minded' and those with antisocial PD or offending histories.

- Referrers for two services felt that service coverage was inequitable and patchy: one in terms of meeting the needs of only the town and not the surrounding areas; the other because coverage was not uniform across the catchment.

- One referrer felt that the siting of the service within a general acute hospital was not appropriate and was off-putting for service users.

- Several referrers suggested desirable developments for the services, such as expanding into antisocial PD and anger management in one case, and practical workshops for another. One felt that the proposal for one service to expand into working with offenders should be viewed with caution and carefully assessed in a research context.

Staff at pilot services

Referrers for four of the services mentioned the importance of the individual qualities of the pilot staff members: attitudes of respect, service users liking them, flexibility and willingness to try new things as well as skill, knowledge and calibre were commented upon. Referrers for two services mentioned the importance of support for these staff to avoid burn-out and the need to value and nurture those who were enthusiastic about working in this challenging area.

Problems were mentioned with sickness and staff absences, or the effects of staff leaving, in respect of three services. One referrer in particular talked of the negative impact this had in terms of consistency for the service user.

> Continuity of care gets lost particularly if there's no recognition that if patients… get ill somebody needs to deal with that patient, not just cancel the appointment, and I feel very uncomfortable when that happens. (R11)

Several pilot services employ a mix of professionally trained and non-professionally trained staff. The skill mix was something that was picked up by referrers, most of whom felt this was appropriate. Referrers for a small number of services, however, reported concerns with the employment of non-professionally trained staff. One told us that they felt that such staff might be challenged beyond their capacity.

> Non-professionally trained people trying to carry caseloads that they aren't experienced or qualified to do and don't have the support networks to manage these really challenging people. I mean there's not a huge number of the really challenging people, but when they do [need help] they're very difficult. (R15)

This referrer also mentioned problems of the, non-statutory, service being too anti-medical-model. Another felt that the low numbers of experienced and trained staff was a problem early in the pilot, referring to a particular service user that they were not experienced enough to work with who nearly 'sank' (R9) the service. Several mentioned that there had been significant changes, and lessons learned over the time that the pilot had been up and running. While referrers felt that most jobs in mental health and social care were demanding, they told us that demands on staff working with this group of service users were particularly high.

Funding and intensity of the service due to pilot funding

Six referrers made mention of the nature of funding for the services. Three of these referred to the intensity of service that pilot funding meant they could deliver. They questioned whether this could be sustained once pilot funding ended and one told us that they felt that these special funding arrangements could provoke envy amongst other services.

> People might be anxious that if they support [the service] their own jobs may be under threat in some way. Sense that perhaps a service is too luxurious or attitudes haven't particularly changed towards people with PD - that services are not necessary. (R8)

Others admired resilience in the face of uncertain funding and would like to see more funding provided.

Dedicated versus mainstream services

A strong theme that came through from most of the referrers interviewed was that CMHTs were not generally well equipped to help these service users. Some told us that their CMHTs excluded people with PD and that the dedicated services had a far more helpful approach. Some referrers felt that the psychiatric approach was unhelpful as it reinforced the idea for service users that they could only receive more help when they were in crisis; that it did not deal well with management of behaviours and emotions for this group and that medication was not helpful. Several stated more strongly that they thought CMHT care was actively damaging for and discriminating towards this group.

> In my experience, mental health services can be quite prejudiced towards people with a diagnosis of personality disorder. Quite damaging often. Because CMHTs are so stretched, people seem to get quite inconsistent services, frequent changes of workers etc. Also get treated quite badly really… some workers in my experience really dislike and talk malevolently about people with PD. (R4)

Those who suggested reasons felt that the less positive experiences in CMHTs may be due to a lack of awareness about, and skills in, managing PD. Others talked of a risk-averse culture which led to fear of some of the behaviours associated with PD, such as self-harm or aggressive behaviour. A third point was that CMHTs prioritised, and were designed for, working with people with Severe Mental Illness such as schizophrenia and bipolar disorder, rather than for working with people with PD.

Dedicated services were seen to be able to offer a respectful and validating environment that was skilled in working with these particular problems and tailored to service users' needs. PD services were perceived to provide better containment for these service users, a greater degree of consistency, a team approach and the ability to work in a group.

One referrer from the voluntary sector felt that having a dedicated service gave the message that CMHTs and outpatient services did not need to work with this service user group and allowed them to let go of their responsibility. Primary care referrers talked about the value of maintaining care, with skilled support, in primary care and the voluntary sector where possible.

Key messages – from interviews with referrers

Regular, comprehensive feedback at each stage of the referral process and clear communication from PD services are important.

Flexible entry criteria and a flexible approach to assessment and helping people engage in the service are considered valuable.

Referrers value PD services, would feel the impact of closure were this to happen, and were concerned about the potential impact on service users.

When working jointly, communication, coordination and transparency are required to keep service users safe.

Training and supervision are important in developing the practice of local staff and helping them to feel more confident in working with service users at risk (but finding time to participate can be challenged in hard-pressed CMHTs).

Dedicated services need to pay particular attention to the personal qualities of staff that the recruit, in order to ensure that they are able to work effectively with people with PD.

4.2.2 Commissioners

Commissioners for each pilot service were approached for interview but those linked to two pilot services were not available. Two commissioners were interviewed in the case of two of the pilots because these services covered more than one PCT area (see Table 2). The commissioners had a range of roles but the majority were responsible for commissioning mental health services.

Initiation of the service

Eight of the 13 commissioners had had direct involvement in the bid to establish the pilot services. For those that had not, it was common for their predecessor to have been involved. Being involved in the process from the beginning seemed to help give commissioners a sense of enthusiasm, pride and investment in the pilot.

Commissioners outlined a variety of drivers for initiating the service. Demand mostly came from existing services in the area, or from a recognition of unmet need for people with PD. Commissioners from two services mentioned a formal needs analysis done by commissioners and local clinicians, one looking at the high use of inpatient beds by PD service users. Another mentioned the gap in services at a multi-agency level. One commissioner spoke of developing the PD service as part of a wider review of services for people with PD including a non-pilot funded day hospital. Several mentioned that service users had been important in the development of plans for the service, by voicing concerns about existing services which they felt did not meet their needs. One was open about the fact that it was quite an opportunistic development in light of the available funding. He also stated that guidance from the National Institute for Mental Health had acted as a driver.

Interaction, impact and outcomes:

From a commissioning perspective, having a demonstrable, measurable impact on other services was an important priority. Several mentioned this as a key factor in decision-making around the ongoing funding of a service. The sort of impact that commissioners were primarily interested in was reduction in high use of services such as A&E and inpatient bed days. Several mentioned saving money on out-of-area placements to residential facilities for PD service users. These put figures on each out-of-area placement at £150,000 to £200,000 per service user per year. They emphasised this meant that only a small number avoided having a big cost impact. Commissioners linked to four services felt the service had paid for itself, in one case, at least four or five times over (C1, C3, C8, C10). Others felt less able to demonstrate this at the moment, and several were asking the services for more data on cost-savings. Several talked about the importance of less easily measurable outcomes, such as user satisfaction, reduced self-harm, increased engagement with services, reduced chaoticness, fewer people losing jobs and greater social inclusion for service users.

One mentioned the difficulty of not necessarily being able to recoup cost savings. For example a reduction in visits to Emergency Departments was not necessarily money that could be recovered. The commissioner also mentioned more tangible cost savings such as reduction in medication use or reduction in bed days as possibly being an area where costs could be actively avoided. Another went on to say that the service needed to show not just cost-effectiveness, but cost-effectiveness in relation to an alternative. For example would extra support for CMHTs have the same impact but for less investment? For some service models, including a preventative service, and a service giving indirect consultation and support to other providers, commissioners felt that cost savings could not yet be proven. One talked about an increased load on the crisis team as a result of the service being in place. This was felt to be because service users had greater awareness of what was available and did not feel excluded from services.

Commissioners also talked about the reduction in use of non-health agencies, such as police, probation, housing or benefits as an important impact of the services. Whilst they saw this as important, it was often hard for them to measure – as it was out of their remit – and any cost savings would not be seen by health budgets. This led several to talk about the importance of considering these services and their impact at a multi-agency level. They felt that someone with PD would have problems that impacted on all areas of their life: therefore the solution should also involve all agencies. Some went on to say that, as the impact would be felt by other agencies, some felt more so than in health, that they should be encouraged to jointly fund and commission the PD services in the future.

Training and consultation

Around half of the commissioners talked about the importance of the indirect service provision that the services carried out. This ranged from raising awareness of the service with other teams, to raising the profile of PD within other services. Others talked about direct training, which helped to change the way others worked:

> [Helping] others to see that the needs of people with PD can be met and not just, if you like, 'oh well they have got PD and therefore that's the excuse for not doing anything' or, 'they are challenging the way in which we have always provided it, why should we change just to meet their needs', so a lot of the negative stereotyping that has grown up in some places, almost part of a culture. (C7)

Another talked about the limitations of the consultation model. He felt that some of the clinicians were reluctant to take this approach:

> They react to that like 'someone's looking over our shoulder but we still have to do the work', so some clinicians are not overly enthralled by that approach. (C2)

He did feel, though, that attitudes would be more positive in time when the impact of consultation became apparent. Some commissioners felt that indirect service provision aimed at raising awareness and skills in other services working with people with PD was an important part of the work of dedicated services. They told us that this was highly valued by other agencies involved with service users, e.g. police, probation, housing, ED, voluntary sector. Two commissioners told us that indirect work was not yet in place. One said that the service themselves thought they were engaging with local services, but the commissioners felt they were not. Another said that the service had struggled to establish its core work, and so had not yet managed to do work with other services, but that this may develop in time.

Local context

Several of the commissioners talked of the importance of integration of the PD service with other local services, but that this was currently compromised by their pilot status.

> Ensuring that they're well integrated into the services, because that's the problem we have, when you set up new services, they always see themselves as unique, and yes, they may have some unique expertise but they have to be integrated into whatever we've already within the system, because they can't sit on their own, they can't sit away from the rest of it. (C4)

Others talked about this more specifically in terms of having a coherent care pathway for service users and planning PD services in a coordinated way across the local area. One of the pilot commissioners was in the process of reviewing all the PD provision in the area to ensure smooth transition and reduced duplication. Others reinforced the concept of awareness raising and 'marketing' (C8) the service adequately with local services to ensure good links. One said that this had been a shortcoming of their particular service as they had not had capacity to do this whilst setting up the service. Some discussed the challenges of this, with the different way of working of the PD service compared to traditional psychiatric models being a barrier for some local teams.

Dedicated services versus mainstream services

Most of the commissioners talked about how much better the PD services were at being able to support service users compared with mainstream mental health and social care services Examples of how these needs were better met were having a network of support, using innovative approaches and group work, and reducing the feeling of abandonment at the end of a service in the case of a user network. One commissioner described the change for service users of moving into a dedicated service:

They don't necessarily always get much of a solution for them, whether that's housing or CMHTs or school system. They generally fail them because they try and approach it from a mono discipline way. What actually they don't understand is that dealing with people in a different way, perhaps less confrontational, perhaps more group based work, challenging but in a more structured way, does have a better effect. (C3)

Organisation and delivery of services

Most commissioners talked very positively about the specific model that was in place locally. In particular their comments were often around how well suited the model was to the local situation, e.g. hub and spoke supporting wider areas, peer support to supplement clinical contact, consultation work for where the critical mass was too small to warrant direct specialist work. Many thought that their local service model was one that could be applied to other areas, both geographically and across other areas of mental health, e.g. peer support network. One area had had specific enquiries from other trusts as to how they could develop a similar model.

Five of the commissioners felt that service user involvement was one of the weaker areas of the service. Reasons suggested were in some cases that there was not an existing body of service users as they had often not had the services before. Others felt, however, that this was a key part of the work, for example service users developing their roles within the service, increasing their levels of responsibility. One talked about teething problems, such as conflicts of interest for service users, and issues around payment of those in responsible roles. As mentioned above, the degree of service user involvement supported did not always match apparent interest from the service user population.

Those commissioners that talked about staff members talked very positively. Several talked about the service leads as being enormously instrumental figures in setting up and maintaining the services. Several talked about the importance of having a significant amount of time to develop a strong foundation in terms of recruiting and training staff and developing links with the local services. Others mentioned challenges in recruiting the right staff.

I suppose a certain sort of naivety in terms of thinking that we could go out and recruit the right people with the right skills sets… needed to be a robust in-house training and support package available for staff, and we have now got that, but as I say, it took a while for the penny to drop but you know, the people with this sort of skills, knowledge and experience aren't two a penny. (C7)

Several commissioners mentioned that the intensity of service provision had had an impact on the capacity of the service: a less comprehensive service could have been delivered to more people. Conversely one felt that their service was still building up to reach their capacity – they were not currently meeting targets of numbers of service users seen – and that low numbers of staff to begin with had been a contributory issue.

Funding

The majority of the commissioners felt that securing funding for the services would be a significant challenge. Most said that when funding was no longer ring-fenced it would be enormously difficult to keep the money away from other priorities such as acute services. Many felt that even if the service was successful, it would be hard to argue for it against other pressures on baseline funding for PCTs. Several referred to the specific financial crisis that PCTs were currently in as a reason for this, and said that the situation had significantly changed since the initiation of the service. Other issues in prioritising funding were PD 'not being a target' (C9) and not being part of the National Service Framework. (Note: While services for people with PD were not included in the original NSF for Mental Health, Special Health Authorities have been required to report on services for people with PD during the last two NSF reviews.) Several mentioned future restructuring with regard to potentially decreasing funding to tier four services and increasing lower tiers due to the change in funding mechanisms from cost price funding to cost per case. Several commissioners had already had confirmation of the money being devolved on a regular basis, but still stressed the importance of securing the money for the PD service within the PCT. Again they emphasised the importance of demonstrable cost savings in supporting the ongoing funding of the services.

Almost all of the commissioners told us they thought it would be a great setback if the PD service did not continue. One commissioner felt the impact would be less great:

> There would be what 12 clients three times a year, what 36, a year that wouldn't be seen. Which compared to the number of acute medical MH admissions we have that is quite a small number. (C9)

Sustainability and development

Many of the commissioners talked about developments in the service being a key part of their sustainability. They felt there was a need to continue moving forward in order to demonstrate that they were increasingly meeting needs of the local area. For some, this was expanding geographically to cover new areas that had been taken on by the trust. For others, this was in terms of creating stronger links with other agencies. Some specifically mentioned greater links with primary care as a priority as it was felt that GPs often had difficulty working with people with PD. One mentioned the planned recruitment of a liaison worker for A&E. Others talked about working more in prisons, in-reach work, or with the police and CJS. Other potential developments were extending the type of service users that they worked with to cover forensic or antisocial PD populations. Others were keen to expand to work in different tiers, for example where there was a tier three / four service, to develop more at the tier two level. One commissioner discussed the risk to sustainability of the service seeming to depend on the clinical leadership of a specific individual. Several had discussed the drive of individual leaders as being key to the service's success, but also saw this as a risk for the future if they left. A solution was thought to be to develop a critical mass of leaders, e.g. more than one lead, to keep moving forward.

Critical success factors of the service

Several of the commissioners felt that there were key factors for successful services. These included:

- A clearly thought out design for the local service model.

- Clear service aims and objectives aimed at addressing local requirements.

- Senior clinical engagement in the other local services.

- Focus on appointing the right staff and training them effectively.

- Demonstration of impact on other mental health services.

Key messages – from interviews with commissioners

Demonstrating a measurable impact on other services is key to sustainability of PD services.

Services need to secure ring-fenced funding to guarantee their future.

Integration with the local health system and close working with other agencies necessary if dedicated PD services are to be sustained.

The service model should be designed to fit the local situation both geographically and in availability of resources.

Time should be taken to build a foundation in a PD service for staff recruitment, training and integration with local services.

4.3 Service users and carers

This section covers the main themes that arose from the qualitative interviews and focus groups with service users and carers in the general order of the interview process, from the 'coming in' process through to outcomes and suggestions for improvement. It is not our intention here to identify the individual sites, but rather to identify the significant themes that emerged from service users and carers at all of the sites.

4.3.1 The 'coming in' process

The 'coming in' process involved a number of possible stages: finding out about a service, expectations, assessment and early impressions before starting to attend the service. Obviously, the significance and experience of each of these stages varied across the different sites, with some presenting more challenging assessment procedures than others, for example.

Desperation and hope

One of the complications for many of the service users approaching any one of these new services was that they were influenced by their previous experiences; many described being rejected, dismissed or treated badly within mainstream mental health services. One of the main reasons they gave for this was the personality disorder diagnosis and / or the complex needs or difficult behaviours associated with the diagnosis.

As a result of these experiences, many service users talked of their desperation for help and a willingness to try anything. They did not feel as if they had any choice about using the service; a significant minority referred to the pilot PD service as a last chance or 'last resort', or told us it was 'this or nothing'.

> It was a case of [this service] or jack shit. There is nothing else available. I don't come under the system for mental illness. I don't have a mental illness. (SU44)

> I was just kind of used to being passed from pillar to post. (SU33)

This desperation and lack of hope was expressed by many service users whom we interviewed across nearly all of the sites. It clearly influenced their expectations of the pilot sites. Some people were relieved and grateful to be offered anything:

> I'm still at the stage where if anyone offers me a service I'm just really grateful, so I'm not really going to criticise what it is. (SU55)

A related issue here is the identification of the service as being a specialist service for people with a diagnosis of personality disorder. Obviously this does not apply to those services that avoided the use of the diagnosis, but for some people this identification of the service meant a great deal, as it implied that the service was designed and intended for them. In contrast to the above-mentioned lack of hope, it raised positive expectations and hope for many people, partly because they had experienced rejection from other services but also because it implied specialist skills and knowledge on the part of the staff. In addition, it meant meeting other people with similar problems and potentially shared experiences, which links to the powerful theme of peer support (explored in Section 4.3.4).

> I also kind of felt that at last there is someone, somewhere that may possibly be able to help with something, whereas before there was no one and nowhere helping with nothing. (SU22)

Equally, some service users felt very anxious and fearful about further rejection, and the possibility that they would have nothing to fall back on. Indeed, some said other services had been withdrawn from them on entering the pilot service, which was a further source of anxiety should they find subsequently that the service was not right for them. Ex-service users in a couple of sites said this had indeed happened: they had no support to fall back on when they left the service.

Information

At the time of the interviews, some of the services may not have finalised the information and publicity they were circulating to local professionals and / or to potential service users. There were mixed views and experiences of the information people were given. In one or two sites, people were simply told by a local professional that it was a new service for people with a personality disorder or with complex needs. This was sometimes enough, but many people would have liked written information to take away and read.

> I would have quite liked a leaflet on the service and what they offered, I think that was kind of missing… now we've got a website but we didn't have that when I started but I think if I could have seen the website when I started, that would have been great because it's got a lot of information on it. (SU19)

Others had received written information, in the form of leaflets seen at local resource centres, or given to them at the time of referral. This was of variable quality; in some cases it was referred to as confusing or unclear, whereas in other cases it was found to be sufficient. Some people reported needing time to absorb the information. In a couple of sites, people felt mental health professionals and GPs needed to have more information to pass on about the new service. Others felt they could trust the information they were given because they could trust the people who had given it.

I had been referred a couple of years previously by a psychiatrist I had a very good relationship with and he assured me that he believed it was the best possible approach for what I was going through. (FGSU15)

The quality of information seemed to be most significant where the service was significantly different from mainstream services, because people did not know what to expect. In a couple of the therapeutic-community-style services this was particularly noticeable: service users did not feel sufficiently informed about the nature of the service they were entering or did not know to expect a predominance of group therapy, for example. In contrast, leaflets circulated about the peer-support network, designed and written with the service users, were found to be self-explanatory for the most part.

Assessment

Service users in six of the services described the assessment process as difficult and daunting, and in some cases traumatic or upsetting. It was experienced as over-long and thorough in some sites, involving tests or questionnaires as well as interviews, and taking place over several weeks. Although some people appreciated the need for a comprehensive assessment process and felt that it engendered confidence in the staff and the service, many talked of the distress caused by focusing on painful past experiences and the difficult feelings this raised. It made a considerable difference to service users if they felt that staff were there to answer questions and offer support. However, there was a general feeling that this was an unduly traumatic process in some sites.

It was all negative, there was no sort of shining light at the end, it was all you know, 'what are your three worst problems?', you know, 'have you ever been abused and who abused you and when?' and it was just horrific… I mean they wanted dates and everything and I had to ask my mum and it brought up problems for her and, very traumatic all round. (SU46)

I found the assessment really difficult; a lot of stuff came up and there was no support outside. (SU11)

In some cases, it was the tools used during assessment that provoked strong reactions; in one site, service users talked of tearing up the questionnaire they were required to complete:

I've ripped it up and burnt it a few times. It got me very, very stressed. It should have a health warning on it. (SU52)

The services that did not present service users with such a difficult assessment process included those that offered self-referral or focused particularly on ensuring easy access. These services did not present quite the same concerns to people around assessment, possible rejection or entering the service.

Assessment was an issue identified by many service users as an area requiring improvement; they strongly advocated the provision of additional support for people during the process, whether arranged externally or by the service itself.

Diagnosis

There were very mixed views, experiences and feelings about receiving a diagnosis of personality disorder. Many of these were influenced by the implications the diagnosis had for accessing services, both in the past and in the present. Many people talked of past experiences of being rejected by services as a result of the diagnosis. The more recent experience – of being offered a service as a result of the diagnosis – gave rise to some ambivalent feelings in people. Whilst some people had been diagnosed with personality disorder some years ago, others had received the diagnosis only very recently, and found out about it in connection with being referred to the new pilot service.

> I said [to the facilitator] 'look, now I've never actually been told I've got personality disorder. I've done this questionnaire thing and, you know', I said, 'have I got PD?' And she says, 'well, you wouldn't be sitting here if you hadn't'. (SU54)

Perversely, it had become the key to a service where once it had been a barrier. The irony of this was not lost on some people.

Many of the service users we spoke to had been given a number of different diagnoses and variations of diagnoses over the years, resulting in a somewhat resigned, if not sceptical, view of the current one.

> Um, before I came here there was lots of different reports about personality disorder, first it was borderline, then it went to severe, and then it went to psychopathic disorder and now, I'm back to borderline, since I've been coming here. (SU7)

Many service users found the diagnosis to be negative, even derogatory and insulting. The terminology itself gave rise to these views: simply being labelled as having a 'disordered personality' was sufficient to give rise to feelings of resentment, anger and frustration. Some people talked about the stigma attached to the label and the possibility of being turned away from mainstream services once again when no longer using the pilot PD service. They felt they had been stereotyped and judged by doctors. They also felt it was unfair to be labelled with a derogatory term when the disorder you have developed is due to abuse at the hands of others, causing them to feel like victims all over again. Some people felt that the diagnosis just did not 'fit' them.

> So when I discovered that I had BPD, I was like 'well, how the fuck have I got BPD?' Because I don't do any of the things that one ordinarily associates with it. (FGSU24)

There were also many people who had come to accept or to welcome the diagnosis, perhaps because they had struggled with mental health services and treatments for many years and found nothing helpful, or because they had come to feel that the symptoms and behaviours associated with the diagnosis fitted them quite well. Some people expressed resignation at this whilst others revealed more positive attitudes towards a label they felt they could, at last, identify with.

> I'm beginning to see actually that's not a disorder that's just who I am. (SU6)

> For the first time I had an answer as to why everybody used to call me a weirdo or an odd-body. (SU54)

> It's hard to accept but it does fit in. It's hard to accept because of the stigma associated with PD… It fits with my behaviours, interaction with other people, being in the mental health system for quite a few years. (SU10)

A few of the services had actively helped with this, giving a positive 'spin' to the diagnosis through providing information and explanation, but also through the sense of belonging engendered by a shared identity with other service users:

> [Other services] don't tell you anything, they just tell you and expect you to know what [personality disorder] is, whereas here you actually get leaflets and get told what it means. (SU7)

> It's not about what your actual label is. It's about 'we're all people' and… You need time and space and you need to know that you are worth it. (SU62)

Early impressions

First or early impressions were important to people; a couple of services made an immediate positive impression when service users entered the service for the first time. People described an air of warmth, friendliness and a welcoming environment.

> My first impression was 'oh my God what have I let myself in for?' but since I walked through the air of warmth just landed you and… and the staff acknowledged you wherever you went and were very kind and very, very loving and supportive. (FGSU1-7)

In another service, where a service user's first introduction to the service was to enter a group, the existing members had been told in advance that a new member would be joining them and consequently they created a welcoming atmosphere. The service for young people provided an easy entry point through a youth service, which resulted in an easy access and assessment process.

Some people were initially reluctant to join groups, or to join a service that focused entirely on groups or group therapy. While some people managed to overcome this initial reluctance through experience, others chose not to attend groups if they had a choice, preferring to access only individual therapy. One service began with a case conference consisting of 18 community members to whom the new arrival had to present their case for joining: many experienced this as daunting and off-putting.

The skills development service attracted most of its service users due to its focus on vocational development, education, training and employment. Those who came here did so because this was something they felt that they needed and wanted in their lives.

Key messages from service users – referral and assessment

Adequate support needs to be provided for people as they pass through lengthy and sometimes traumatic assessment procedures for entry to a service.

Consideration needs to be given to the experiences with which people come to the pilot services and the desperation and hope with which they may be approaching this new service.

Clear and accessible information needs to be provided about a service, both to local professionals and to potential service users and carers, particularly where the nature of the service is very different from mainstream services.

4.3.2 The service model

In this section we begin to see the significance of the service model for the service users, both in terms of general satisfaction and in relation to specific elements singled out for praise or criticism. Some of the pilot services were clearly experienced as being more complex than others in terms of the different service options or stages available to people. This inevitably resulted in more complex responses by service users.

Different aspects of service provision were picked out for praise in different sites and by different people, with the strong implication that no one service model or approach fits all. There were some strong overarching themes, however. Features highlighted as positives by service users were flexibility and accessibility, the role and qualities of staff, peer support and the provision of good out-of-hours or crisis support. Some services were praised for providing long-term support, as opposed to the inadequacy of short-term support received in the past from mainstream services. Several services were praised for helping people to work through their problems in a safe and supportive atmosphere, often through the medium of psychotherapy.

Flexibility and accessibility

The themes of flexibility and accessibility or responsiveness were highlighted in several different services. In some ways, these words are easy to articulate and rather more difficult to pin down in relation to service provision. For many people, flexibility and accessibility were embodied in the attitudes and roles of staff, which we explore in more depth in Section 3. The facts that staff were present, available and responsive to the needs of service users, were all features highlighted by service users.

> I've also been told that at any time that I need to I can phone up and I'll be able to speak to someone, either C if she's around, or if not, one of the group therapists, or if not somebody else will be able to speak to me. So it's like, it's gone from me having no support at all to three times a week plus whatever else I need. (SU81)

In one service, the service users were able to contact their care coordinators by text or phone and reported receiving quick and supportive responses; the care coordinators themselves were described as accessible and flexible in the ways they responded to clients. In another service, service users could access their therapists by email, and again highlighted this as a key positive feature.

> You can sit on the computer and just pour out everything and I've found that really helpful because I'm not good on the phone. (SU16)

Another feature of flexibility and accessibility lies in the overall service model providing a range of service options to choose from, or to access at different times. Services where this was the case received very positive comments. In one service, for example, service users could book 'one-to-one' sessions with staff, and phone-support calls, alongside accessing groups, but could also ask for unplanned support if needed. In addition, crisis beds were available to them. In one service, there was an Open Clinic every day from 9am to 10am which, again, was highlighted as a positive element of the service. The flexibility of telephone support and other means of accessing or communicating with staff, such as texting and emailing, were appreciated by service users in the services where these were in operation.

> They've been really helpful. I mean, like, if you're having a bad day like, and you just call up and you come in, you can speak to one of the staff and I don't know, make it not seem as bad as what you've been thinking it has been sitting at home on your own… and you come and just relax for a bit, a couple of hours and then go back again. (SU7)

Service users valued the flexibility and consistency of the support available at another highly praised service; many spoke about the relaxed atmosphere, and several people said they felt reassured that therapy was not dictated by time limits but by recovery. Service users described this service as a service that listens, understands and cares, with no time limits or pressures, and one with a community spirit that works with you rather than against you.

A sense of belonging

Many service users talked of finding a strong sense of belonging within the service. For most people, this was associated with the specialist PD focus of the service, or the ability to identify with other service users, coupled with the relationships established with staff. For some, the service became a family or community.

> I did feel quite low on Monday and then left quite cheerful because the one thing that I am feeling is a belonging with some of the others. (SU49)

> It's just the fact that the [service] really is a community. That I find incredibly helpful because I think for years you know I've been looking for a sense of belonging and it's just evaded me so many times and… Here you really get that strong sense that you belong you know. (FGSU1-7)

This issue is strongly associated with peer support, and hence also arises in that section. However, it also links back to the desperation and hope with which people approached these services, having often found rejection and dismissal elsewhere.

A positive focus

A theme highlighted by a number of the service users was the positive focus of a service: the fact that it seemed to be helping them to move forwards, and that staff believed in their individual capacity for change and improvement. This was significant for the many people who had negative experiences of life as well as of mainstream services.

> This is the only service that is concentrating on getting me better, everything else seems to be just keeping me in the same place, everything else is about keeping me stable and keeping me, um, so I don't tip back over the edge. Here they're willing to push me over the edge if it involves me making steps forward. (SU46)

In at least one site, this positive focus had begun to emerge into discussions about recovery, both on an individual level and in relation to the focus of the service as a whole.

Psychotherapy and group process

Psychotherapy, whether individual or group, stimulated a range of views and feelings. Many people acknowledged that it was complex or challenging but also helpful or positive in terms of helping them to engage with their difficulties. The support of therapists was also valued and appreciated. Therapy was highlighted for helping people to understand themselves and their behaviour better, and for the opportunity it provided to practise behaviours or communications in a safe environment. Therapy was identified as one of the elements in a service that led to significant changes and positive outcomes for people (see Section 4.3.6). Some people gave very positive feedback about DBT in particular, including a Skills Group which taught people new ways of thinking or coping with things.

DBT… actually teaches another way of thinking which… I didn't know was possible. (SU6)

[The Skills Group] is almost like going to college and learning how to … and learning about yourself and relationships and the way your mind works and the way to prevent, you know, things going wrong and or, or the way to accept and it's just so invaluable, it's just changed my life so much. (SU13)

However, there were also some negative comments about therapy, particularly, it seems, where people felt they had little say or control over the way it operated. A small minority of service users described therapy as humiliating or patronising; one said it caused her to behave like a child. There was a general plea for individual therapy where group therapy was the only option.

Group therapy aroused some mixed feelings. Many service users expressed reservations about group therapy on joining a service, although some went on to find it helpful or surprisingly positive. In particular, people valued the opportunity it gave for peer support and for sharing problems and experiences with others. Some service users had come to appreciate the benefits of group therapy even if, given the choice, they would have preferred individual therapy at the start. They felt the professionals had known what was best for them and that they had made more progress in a group and community setting.

However, in one service, where individual therapy was not an option, the groups became highly charged and a few people reported leaving the service because they found the groups unhelpful or 'a waste of time'. In a couple of other services, the main concern was that service users did not know or understand the 'rules' or the way in which the group was supposed to operate. Some wanted to ask direct questions of therapists and found they received no responses, leaving the other service users to let them know that they could not expect to receive direct responses from the therapists:

You know, we need some kind of response and, if it was made clear initially that those responses don't exist, it would be easier to deal with. But it is not and it is so frustrating. (FGSU29)

In all of the TC services, service users expressed concerns about groups designed to prepare people for entry into the full therapeutic community, referred to variously as the MAC group, Options Group, TAC. Their concerns were focused on the degree and quality of support on offer in the therapeutic community at this stage leading to a reluctance to open up and talk about difficult issues. In some cases it was felt that the group was too large for people to have much time to talk or gain support, and that they could be left with difficult feelings at the end of the session. Others were concerned that there was no one-to-one support or peer-support phone line at this stage. In one site, service users felt unclear about the rules and boundaries and did not know how to support each other. Either way, service users said they were reluctant to raise difficult issues that might not be dealt with within the time available. A few people expressed concerns about the ending of therapy, explored further in Section 4.3.10.

Boundaries and rules

The existence of boundaries and rules was a contentious issue for many service users in certain services. The degree to which rules were made explicit and transparent was an important mediator for people, as was the extent to which they were open to negotiation. In addition there were some specific rules that gave rise to strong feelings.

In some of the TC services, rules or boundaries seemed to be implicit; some service users felt that they had to find out about the rules as they went along, often from other service users, and they felt frustrated about this. This applied to the way in which group therapy was conducted, but also sometimes to the boundaries maintained between staff and service users. In one site, service users talked about the rules being written in a handbook but interpreted differently at different times depending on the current membership. In another site, service users talked of the different conditions surrounding the provision of therapy, for example, not missing more than three or four sessions in a row and being required to attend group sessions in order to receive individual therapy. People were not entirely comfortable with these conditions and felt they were non-negotiable.

Perhaps the strongest feelings were aroused in relation to the rules operating in some of the services concerning peer relationships and friendships. These were felt by many to be too rigid, and also impractical in some instances. For example, one service user reported being told that people were not permitted to travel together to and from the service on public transport despite the large geographical distances involved and the poor public transport service.

Another rule or policy that received a lot of criticism was the one concerning medication. In the therapeutic community-style services it was required that service users come off psychotropic medication before, or shortly after, joining the full therapeutic community. This was a source of some anxiety and distress for some people, who felt they needed the medication or that there was insufficient support available to take its place.

I am just not happy about the medication thing… I mean, I am living alone. I can't not have meds… You know, to go home, three days to me is part time anyway, you know, nine 'til three, and then to have to go home and face all my demons and all… you know, what if I start seeing things again? What if I start getting aggressive, drinking, all sorts of things that some of the medication might just dampen down and I have got to go home on my own. (SU49)

Conversely, some service users appeared to agree with the medication policy, suggesting that therapy might not have the same effect if medication was altering their perception of, or ability to feel, the full range of their emotions. In addition, some service users saw the policy as giving them positive encouragement towards permanent freedom from medication.

Some services operated strict rules surrounding self-harm; for example, people were not permitted to ring the peer-support line if they had already self-harmed; or reported that they had to stop self-harming before they could move on to talk about other issues of importance to them. One woman, who had experienced a bereavement the year before, was not permitted to discuss this until she had stopped self-harming. In one service, service users were not permitted to self-harm on the premises nor to talk about certain potential 'triggers' to self-harm, such as the use of drugs and alcohol.

There were mixed views about these rules; some service users could appreciate the need for them or the benefit of them, whereas others were far more critical of their inflexibility. Some people felt that boundaries helped them to feel safe so long as they were applied consistently. A key mediating factor in all of this was whether or not the rules were open to negotiation. In one service, where service users felt that they had more input into creating and influencing the rules, they were less critical of them and appeared to feel a greater sense of 'ownership' of the rules.

We… as clients of the [service] we make our own policies… Sometimes I disagree with the policies… sometimes I agree with them but then you go by the majority which is a good thing… Our rules and regulations are a hell of a lot stricter than what the mental health institutions are. Because we want the place to run properly… we want it to be a safe place for everyone. (SU1)

Crisis / out-of-hours support

The absence or inadequate provision of crisis or out-of-hours support was raised as an issue in some of the services. In one service, for example, it was expected that people contact their own GP or CPN or go to A&E if they experienced a crisis when the service was closed; otherwise, during service hours, they could call a special crisis-group meeting. There was some dissatisfaction about this, as people pointed out they did not tend to have crises during the hours of nine to five when the service was open. At another, service users were critical of the crisis support made available to them by a local crisis team, saying they would choose to use other services such as the Samaritans or friends and family. One of the issues raised by these service users and those at another service was that staff would respond inappropriately to someone in a crisis. Similarly, in another service, service users said they would choose to use alternative services rather than contact the PD service in a crisis.

> People like us, it's at night when you get lonely and you've done everything you wanna do for the day and then you're on your own at night and things start going through your head and you can't phone any of them 'cos there's nobody here 'cos they're shut. (SU47)

Services that received praise in this respect were those with a responsive and person-centred out-of-hours service that people could access when they needed it.

> If I was in crisis I would just pick up the phone and I might just need to talk to them… they're on the end of the telephone. (SU1)

> They have a text, so you don't actually have to phone them, you can just text them anything and say 'help' – and then they'll ring back. (SU7)

A couple of the sites were rather different in this respect. The skills development service did not aim to provide comprehensive support to people and therefore, perhaps, did not raise any expectations in relation to crisis support. An out-of-hours peer-support line was planned at the other, with the intention it be run entirely by the service users. However legal, and health and safety, concerns within the Trust had led to severe delays to this, and at the time of interviewing it had not been established. People were critical about this, although many were also concerned about the responsibility and the need for the service users running the line to be well supported themselves. It was a feature of most of the services that they sought to enable people to prevent or pre-empt a crisis, and many of the service users commented on this. In one service, contacting the crisis service to talk to someone had helped to prevent self-harm:

> That was the only thing that sort of stopped me from [taking an overdose] again… they calm you down and make you think straight. (SU33)

Key messages from service users – the service model

No one service model or approach fits all: some degree of choice or a range of options needs to be made available to service users.

> Some degree of transparency about therapy would enable people to understand, and perhaps therefore appreciate, the approach taken by therapists in both group and individual therapy.
>
> Good, accessible crisis or out-of-hours service was a valued part of some services.
>
> Boundaries and rules need to be carefully dealt with, transparent and consistently applied; a degree of flexibility or open negotiation can increase service users' understanding and appreciation of their role and value.

4.3.3 Relationships with staff

> Other services where I've been in, the staff are always in the office, the doors always shut and like, none of them could be bothered to get off their chairs and come whereas here they're in the lounge, one of them is in the lounge, one in the smoking room, having a one-to-one, maybe one or two of them are in the office dealing with, like answering phone calls, for crises. (SU7)

The role and qualities of staff constituted a remarkably consistent and positive theme across all of the services. Many positive comments were made about members of staff and stark comparisons were drawn with staff encountered in mainstream mental health services. Staff were described as:

- non-judgemental
- helpful, supportive
- caring, understanding
- genuine, 'real'
- positive
- flexible, accessible, responsive
- skilled, knowledgeable.

In addition, it was important for service users that staff treated them as 'whole people' rather than focusing solely on their negative characteristics, symptoms or diagnosis. Below, we have grouped some of the positive characteristics into themes in order to understand some of the ways in which staff created a positive environment for service users.

A key quality identified by service users was that staff were accepting and non-judgemental of them. This was a vital component of the staff of a service that was accepting them as service users and as whole people.

> The only person I contacted and could trust… who wouldn't judge me or what I was doing. (SU33)

> I'm acceptable, first time I've ever felt accepted. (FGSU1-7)

Many people highlighted the responsiveness and accessibility of staff: the fact that they could be telephoned, texted and / or emailed – and would respond – was highly valued. At the young people's service the support provided was almost entirely reliant on the relationships formed between service users and their care coordinators. These members of staff were enormously valued by the young people using the service. They were valued for their accessibility and responsiveness, and were described as reliable, friendly, supportive and understanding. In addition, it was important to the young people that their care coordinators were 'unshockable' and 'not afraid'. Several of these service users described the service or their care coordinator as 'a lifeline'.

> He's more like a friend, but he's not as it's not personal. (SU36)

> When I am with him I feel good about myself. (SU35)

In a couple of services, service users appreciated the fact that staff came over as genuine and 'real', that they were honest about themselves to some degree whilst maintaining realistic boundaries.

> I trust them all. I think they're all wonderful and um, I'm actually quite protective of them… they're honest with us and if they're having a bad day, they'll tell us… and they're more sort of friends than staff. (SU46)

Again, in a couple of services, the positive approach of staff was highlighted: the fact that staff believed in the service users and their capacity for change, encouraged and supported them towards achieving their goals. This was notable in the skills development service where service users were encouraged and supported towards educational and employment goals, but also in another complex service where service users were facing some difficult personal challenges.

In a number of services, interviewees highlighted the equality that they felt existed between staff and service users, an absence of barriers or of the traditional 'them and us' ethos. Ways in which they observed this varied; some staff would cook or share meals with service users or spend break times in their company, they might dress similarly to service users or share some aspects of their lives that would enable service users to see them as fellow human beings.

> We all pull together, it's not just like the staff and then the clients, it's like everybody pulls together, that's how it works here and that's how it keeps going really. (SU5)

For some people, it was important that the staff were skilled and knowledgeable about personality disorder, in a way that staff in mainstream services might not be:

> They're clued up, you know, to the hilt about PD as much as they can… and they do they give sound advice and very good advice. (FGSU1-7)

Criticisms of staff were relatively few. Most comments arose in relation to the difficulties encountered by service users in one or two of the therapeutic community services where group therapy had proved a challenge. A lack of flexibility in the relationships between staff and service users was identified, as was the tendency for staff to be unresponsive or make few interventions in group sessions. The latter relates to the lack of clarity about the model of psychotherapy or the way in which such transactions are expected to work, as mentioned earlier. In one service, there was concern about disagreements between staff and a sense that staff relationships were strained.

In a couple of the TC services, it was suggested that staff were spreading themselves too thinly in the process of setting up new services, or were less available due to cuts; some service users were concerned that staff were not as consistently present as they had been at first. In a couple of other services, service users also expressed concerns about staff absences due to sickness or maternity leave causing inconsistency.

A violent incident in one site, shortly before the interviews took place, had resulted in some service users losing confidence and trust in the staff of the service. They felt that the incident had not been dealt with appropriately – that staff had left it to service users to intervene – and, as a result, they felt less safe in the service than they had before the incident.

Key messages from service users – relationships with staff

The quality of relationships and attitudes of staff were highly valued across all pilot services.

Recruitment of staff and training needs to take into account the need to promote and sustain these valued qualities, skills and attitudes.

Similarly, staff supervision and support needs to be adequate to sustain staff in these valued roles.

4.3.4 Relationships with other service users

A powerful theme to emerge from these interviews was the role and value of peer support. In some services, this was seen as the most important or most highly valued feature of the service and was described with considerable passion. However, peer support did not emerge as a theme in all of the pilot sites. In some services, due to the model of service provided, peer support could not feasibly develop as service users rarely met each other during the natural course of attending the service. People were seen largely on an individual basis, and user involvement was in its infancy.

In the remaining sites, there were differences in the extent to which peer support was promoted or encouraged to develop. Some services operated limited elements of peer support, such as a peer-support phone line, or peer-support board on the internet. In some sites, formal structures were in place to develop and make use of peer support as a feature of the service. This was true of the peer-support network, in which one-to-one contact with staff was discouraged, but people were actively encouraged to meet and support each other away from the service.

Conversely, in the TC services, the fact that social contact outside the service was forbidden discouraged the growth of these relationships into friendships. As we have seen earlier, some people were critical of the service creating this boundary. Nevertheless, people valued the support of the people they encountered in groups with whom they could identify and share experiences. For a couple of people, this was the most important aspect of the service.

> Everything that I say, you know, or do stuff, like locking doors and checking and, you know, getting flustered and it's, it's just everything that I'm like, they're exactly the same so we, we get on like a house on fire and have a right good laugh. (SU54)

Benefits of peer support

Service users discussed many benefits gained from peer support; for some it was the most valuable aspect of the service, a turning point, and a key element in their journey to recovery. Many service users appreciated being able to share experiences with people with similar problems and gain support and ideas for coping. For others it was important to discover that they were not alone with their problems.

> I think it helps your mind knowing that other people are suffering as well… it means, um, like, recognising myself, knowing that I'm not alone. (SU47)

People often talked of peer support specifically in relation to the sense of shared identity or shared understanding that came with sharing the same diagnosis or symptoms and behaviour associated with the diagnosis. This was clearly enormously important to some people, regardless of the service model in operation.

> You realised that you weren't the only one feeling like that, there were other people in the world that felt the way that you did and being able to talk to them and hear their experiences of how they were dealing with it was helpful. (SU23)

In a few services, the service users described an all-embracing sense of community or family that included both service users and staff and engendered a sense of commitment and belonging.

> I know it sounds strange, but we are like one big family, like when we're all together – everybody helps everybody else. (SU5)

In some services, people talked of extending relationships with each other beyond service hours, developing friendships and supporting each other through a crisis. In the peer-support network, people talked of meeting and supporting each other both within and outside the group meetings, and texting and sending cards to group members when they were unwell.

> A network of people who know you're alive is just wonderful. (SU66)

A couple of people had been very isolated prior to attending a service; attending the PD service was the first time they had felt part of a social network.

> I didn't have any friends once I came out of hospital but I came here and I made friends and the groups weren't anything like I thought they were going to be, they were just relaxed and cool. (SU7)

Finally, there were some service users for whom helping others through the process of peer support was highly valued. In one or two cases, people almost seemed to be surprised they could come out with a piece of advice or a suggestion that might help others. In doing so, they seemed to help their own progress and self-esteem.

> We all seem to be supportive of other people, whereas again that is what you don't get when you go and sit in front of a shrink. You don't get that support and you don't get that opportunity to support somebody else. (FGSU30)

> Giving support is one of the most therapeutic things I did. (FGSU14)

The challenges of peer relationships

Spending long periods of time together in an intense atmosphere with some challenging difficulties to deal with sometimes led to tensions: 'sometimes it feels like trench warfare'. For a few people in services where peer support was the primary focus, it was sometimes difficult to get the balance right between giving and receiving support; they sometimes found that their own needs were not being met and needed to seek support elsewhere. Similarly, in a few services, some people talked about continuing to feel concerned or anxious about their fellow service users outside of groups or service hours, or 'taking on' other people's problems.

> Its just too many people's issues to deal with because I take it all on board and I go home and that's it for the week I've got everyone's problems as well as my own. (SU52)

In a couple of the sites, service users talked about the development of 'cliques' within the community and tensions forming around these with the potential for some people to feel excluded. There were a couple of occasions where this had become a problem, and service users were concerned that staff were either not aware of it, or did nothing about it.

I'd like [staff] to be more aware of what happens when people are outside having a smoke, a cigarette and things… There is this, like, group of people, little cliques, that don't have those values and focusing a lot of energy on putting people down… So I'd kind of like a bit more support on how to handle that, but it's really awkward because what I've got to do is actually take it into the group meetings, but then it's fear of you being on the receiving end of whatever is happening if you actually speak up. (SU51)

Key messages – relationships with other service users

Peer support is a highly valued element of services, and can be usefully supported to enable people to get the most out of the support and friendship of their peers.

Care needs to be given in services where peer support is the core of the service, to ensure that adequate support is in place to sustain it.

There needs to be some provision in place for people to talk to staff about difficulties that arise between groups or cliques in a community.

4.3.5 Service-user involvement

Service-user involvement was explored at different levels within the service: involvement in individual care and treatment, in different elements of the service and in the overall service planning or delivery. There was a general feeling throughout the pilot sites that service users were genuinely listened to, that their voices were heard, and this was highly appreciated by people. Many service users across different services spoke positively about feeling involved in decisions made about their own treatment or care. One example given was the way in which care reviews were handled at one service: service users felt that they were consulted and involved in their care reviews and that their opinions were listened to. In a couple of services, service users spoke of having their own support plans and feeling very much in control of the support they received.

I think there's nothing that is done without my consent… the very process of therapy is in-between the hands of my individual therapist – obviously she's the one who's qualified to do that, but every change or every step… is discussed anyway. I can, I've got the choice to stop at any time if I want to. (SU15)

Nothing actually gets done without my say so. (SU37)

In a few of the services, there were service users who expressed more ambivalence about their sense of involvement. In one, there were some service users who did not feel that they were involved in their own care or in the running of groups. In another, some felt that, although they were consulted about their care and treatment, ultimately it was the therapists who held the power and made the decisions. Nevertheless, in some of these services all members of the community, including the service users, have the power to vote to accept or reject new members, and to apply the rules or boundaries.

In many of the services, service-user involvement in a broader sense was still in development at the time of the interviews. A few had begun to establish forums or community meetings, many of which had been poorly attended, difficult to participate in or resulted in little change to date. In one or two of these, it was felt that these meetings could potentially develop into something useful and user-led. In one of the TC services, service users had been involved in contributing to and updating the handbook given to new members. In another service, service users had been involved in designing and writing the publicity leaflets. However, in general, whilst many service users talked of feeling involved in, or consulted about, their own care and treatment, few talked of their involvement in the wider running or management of the service. Two services stood out in this respect, both of which had set out to be user-led or to actively involve service users from the start.

One of these held regular community advisory meetings, through which service users could influence decisions made about the day-to-day running of the service and the rules about acceptable behaviour. There was also a suggestions box in operation, and service users took part in interviewing new staff as well as participating in a research group that was evaluating the service. The service users displayed a sense of ownership of the service which was unusual amongst the pilot sites:

> You know it would be totally different if it was just the staff taking the decision. It's not, it's the client community that takes that decision and we're a bit tougher than the staff. We make the rules as the community, and for good reasons. (SU2)

The other service to engage more actively with service users was established as a peer-support network. Here, the aim was to enable service users to take on more of the responsibility for the groups and the support through first establishing groups with staff facilitators. Here too, many of the service users expressed a sense of ownership of the service and a commitment to sustaining it:

> It's our decision whether to go or stay… we make decisions about the groups we want. (SU67)

One member of this network said that if she had a complaint or a problem with the service, she would take it to the group 'so the whole group can discuss it and work through it'.(SU42)

However, there were criticisms of the length of the initial consultation period for this service, and of the delays to establishing some of its more user-led aspects, such as the Lead Service User role and the peer-support phone line.

In both of these services and in some of the other services too, we interviewed people who had become involved in regional or national events about personality disorder, attending seminars and conferences and speaking about their own experiences. Those who had done this were enthusiastic about the opportunities it had given them to appreciate the wider context and to feel valued by the service. In only one service was it felt that this kind of activity had been dismissed or discouraged, and they were highly critical of the service for doing so.

> Key messages from service users – service user involvement
>
> Many people valued the recognition, value and empowerment they gained through service-user involvement.
>
> Service-user involvement was underdeveloped in some services at the time of the interviews; there are ways in which some services could extend and develop methods of involvement, to enable service users to have more say in their own care and in the day-to-day running of the service.

4.3.6 Outcomes

Questions about the outcomes that service users felt they had gained through attending the PD pilot sites gave rise to a wealth of information and feelings about personal change. Nearly all of the services had been beneficial to people, many of whom spoke movingly about the changes they saw in themselves. Most service users across most services spoke of changes in the way they felt about themselves, changes in behaviour; of understanding themselves and their behaviour better; and of changes in the ways in which they related to or interacted with others. There were only a couple of services where service users discussed negative or insignificant outcomes.

Two services stood out as having exceeded people's expectations. The service for young people was described in particularly powerful terms when it came to outcomes; some of the young people had seen 'massive change'; 'I've got my life back'. Two of these young people said they would not be alive today if it were not for this service. It seemed the service had given them a lifeline in the form of the care coordinator: someone to stand by them and almost bear witness to their lives and experiences.

> I feel less in fear… it feels like an army has been created for me. (SU38)

> Before, I didn't have a future. Now I know I am strong as a person and have a future. (SU35)

The other service to have exceeded expectations was described as going beyond the individual therapies and service elements and becoming a community or family. Service users' degree of involvement in the service led to a sense of belonging and responsibility. In many ways it was an all-embracing service which, for some people, meant that they needed little outside the service.

Well the therapies are good but it's not just the therapies… it's everything all together. (SU1)

This was potentially a problem for family carers, however; one carer talked of feeling somewhat excluded from what was going on for his wife.

Across different services, many people talked about experiencing changes in the feelings they had about themselves. People talked of increased confidence and self-esteem and of becoming more assertive and independent. Probably the most common word to occur within the whole section on outcomes is 'confidence'. These changes in feelings were attributed to a variety of causes: peer support and the sense of community in the service, the experience of psychotherapy and therapists, members of staff and fellow service users.

They've really raised my confidence and through raising my confidence they've shown me that I've had purpose and that I have abilities that were quite frankly written off by… psychiatrists years ago. (FGSU1-7)

Many service users talked of improved self-awareness: understanding their feelings better, coming to understand their behaviours and to recognise early warning signs or triggers for themselves. Very often, these changes were attributed to group or individual therapy but peer support and the sharing of experiences with others also figured highly.

The [service] is trying to get me to notice warning signs before impulsivity kicks in. (SU3)

Changes in behaviour were also mentioned by many service users. Some people talked of reducing or stopping self-harm or alcohol consumption; others talked of making less use of A&E services, of having fewer crises or managing them better, of getting out of the house more or of managing to leave hospital. These changes were sometimes put down to the service itself and its boundaries or rules, to the support of peers, the attitudes of staff and / or to therapy or therapists.

Since coming to [the service], I'm actually getting out of hospital now – which is a major step and my self harming has improved so much. (SU5)

I've stopped taking drugs, I've got my life back on track, I do things now, I don't hide away. I don't shy away any more, I don't use drink and drugs to get away from things. I am able to stand up to people. (SU33)

Many people talked about improvements in their relationships with others, improved communication skills and interactions with people and making new friends. These changes were largely attributed to the network of people they encountered in the services: the support of people who are able to share experiences and understanding. Some of these changes were put down to the skills and experiences learned in therapy, which was often seen as a medium through which things could be worked out or practised.

I think it's the opportunity to work out things and practise relationships with, come to a safe, safer place to practise ways of being… to practise getting angry, knowing that everyone is not going to leave you when you're angry. Seeing that you can make mistakes and that you, if you sit with it and work it through, that the world does not stop revolving. (FGSU37)

Another theme to emerge encompassed learning new coping skills, new ways of thinking about things or new ways of coping with, or managing, feelings. As well as learning to manage anger better, some people talked of coping with the desire to self-harm by doing something else, such as picking up the phone to talk to someone instead of self-harming, or using a less harmful means of releasing the feeling.

For some people, an important outcome was learning to care about and for themselves, and to allow others to care for them. Through this it had become possible to reduce self-harming behaviour:

Taking better care of myself, perhaps. They encourage us to look after ourselves and take better care of ourselves. So I've perhaps been spending a bit more time looking after me. (SU81)

[They've] taught me to care about myself for a start which means that I'm less likely to self-harm. (FGSU1-7)

Although vocational outcomes, such as employment interviews or training, were predominantly mentioned at the skills development service, people in other services also talked of managing to remain in work or to think about work or study again as a result of attending a service. This was attributed to the rise in confidence and self-esteem, but also to a positive attitude or a sense of hope engendered by a service.

Facilitators of change

As we have seen, the primary elements of services that were identified as facilitating change were often the people: staff, therapists and fellow service users. Therapy itself was seen as an important change agent, as was peer support. Hope was a powerful theme that emerged in several services. Some people found hope in seeing others improve and recover around them; other people found it in the positive and encouraging attitude of staff and therapists.

For some people, an important element of the service was that they felt listened to; this had enabled them to feel more in control of their lives – as against feeling themselves to be the passive recipients of services and professionals. This theme emerged in quite different services: a peer support network and a therapeutic community.

[In other services] other people have the control; they could section me, they could force me to take medication, they could choose what treatment I could and couldn't receive… and yet, here, I feel coming here, it is like I have control over what happens in my life. (FGSU28)

Another vital element in the change process – in the view of the service users – was the sense they had of feeling genuinely cared for in a service. The sense that staff and other service users cared about, and for, them and created an atmosphere of care, could engender positive feelings within them that could move towards change.

> As time's gone on I've found that people around me, staff included, are just so genuine and caring it just becomes easy to start talking to people, you know clients as well as staff and… I believe I've a bit more confidence through it… that's true for clients as well as the staff. (FGSU1-7)

Negative outcomes

> In a couple of the services, there were a few people who felt that therapy had been damaging to them: that the emotional demands of psychotherapy had proved too great or that therapists themselves had caused distress. In addition, a small minority of people found therapy to be humiliating or distressing.

> I think just, as I say, I've been more apologetic for everything and more conscious of what I'm doing and I think more insecure; I think it's going to have a detrimental effect on my life rather than a positive one. (FGSU9)

> I'd like it to be a bit more clearer why I'm there and what it's for, rather than just coming away every time and just feeling even more angry… I'm feeling worse, I want to sort of cry. (FGSU11)

In one service, it was younger service users who felt most dissatisfied with the therapy and support on offer to them; one felt compelled to undertake DBT or she would be obliged to go back to work, which she did not feel able to do. Finally, some service users attending the service in which the violent incident had taken place identified negative outcomes from this incident, including reduced trust and confidence in the staff and feeling less safe in the service as a whole.

Key messages from service users – outcomes

Many very positive outcomes were reported by the service users in this study, often attributed to the other people present in the service: service users, staff and therapists.

Outcomes for some people were as much about process and experience as they were about hard or measurable outcomes; it is important to take these 'softer' outcomes into account.

Several service users found psychotherapy demanding and a minority reported feeling damaged by this.

This is an important section, as it gives space to those people who were in the minority in the services for a variety of reasons. Within individual site summaries, it has been difficult for us to represent these voices fully, because of the possibility of identifying individuals. The majority of service users across the sites were white (British) women. This meant that men were a minority in most services as were people from BME communities. Sexuality was also an issue in a couple of the services, due to the presence of a large minority of lesbian women. An important point to note is that a community may develop its own culture which may then be difficult for some people to participate in for a variety of cultural and access-related reasons.

There were some positive and some negative comments made about the capacity of different services to address issues relevant to minority groups. A couple of services were described as open and genuinely welcoming to all; a transgender person in one service was pleasantly surprised by her reception and acceptance into the group. Some people did point out that they were themselves a predominantly white and female group, and suggested the service should make an effort to reach people who were not well represented.

Concerns were expressed in a couple of services about the gender imbalance being potentially difficult for men coming into the service. An observation made by one male service user was that personality disorder in men tends to be criminalised; he suggested that the service consider how it might develop to take account of this. In another service, where there were some BME service users, concerns were expressed about the way in which staff had responded to racist and other discriminatory remarks made in a group session. The service users who expressed these concerns felt that staff would benefit from group-work training and clearer anti-discrimination policies.

> I do not expect to be in a therapeutic group where someone comes out with all sorts of stuff like 'niggers, pakis, I hit my gay friend'… I do not want to sit in a group and have those remarks go unchallenged. (SU40)

Equally, concerns were expressed in a couple of services about the potential for the significant presence of lesbian women attending the service to present difficulties for some heterosexual women coming in to the service. Many of those currently attending these services did not express these concerns about either gender or sexuality for themselves; rather, they appeared to be concerned for new people coming in to the service.

There was some suggestion from a few people at a couple of services that it might be more difficult for someone who does not fall into the majority group of service users, i.e. white and female, to find the service helpful. In one of the therapeutic community services, the service users who were most critical about the service were those from minority groups. They did not feel that the service was adequately meeting their needs. In another service, people expressed concerns about literacy and language where English was not a first language.

Key messages from service users – diversity

The tendency for these pilot services to be dominated by white British women means that it is vital for them to take into account the needs and voices of the minority groups also served by them.

Training, supervision and group work should take the needs and priorities of minority groups into account.

4.3.8 External factors

External factors include a range of features and issues impacting on the service from outside the immediate remit of the service itself. Location was one key issue to affect a number of services and service users, particularly those based in rural areas. In a couple of sites, service users were concerned about the travelling distance, or about not being able to attend as much as they would wish to. In one service, which covered a large rural catchment area, some people would have to make a 70-mile round trip to attend. However, even in a London-based service, there were concerns about access for people in one borough because the service was based in the other of the two boroughs it served. With the frequent mergers of NHS Trusts, catchment areas are constantly becoming larger and making access more of an issue.

Some people commented positively on the venue and facilities available at the service. Several services were praised for their pleasant, welcoming and safe environments; the fact that a service was not based in a hospital setting, or did not look like one, was important to people. One service was based in a house with its own garden, was on good travel routes and close to the town centre in a nice, quiet location. Due to resource problems in the local mental health services, this building was due to be sold and there were significant concerns amongst the service users about possible new locations. These included fears about experiencing stigma from members of the wider community into which the service might potentially be relocated.

Equally, some comments were made about facilities being too cramped and noisy and lacking in printing and internet facilities. In a couple of sites, service users expressed concerns about funding and behind-the-scenes politics. In one TC service, it was thought that funding cuts had affected the number and availability of staff at the service; it was thought they were increasingly being spread amongst competing services.

4.3.9 Carers

Overall, few of the pilot sites had begun to offer support specifically to carers at the time of the interviews. There were signs that this was changing, but as a result it was difficult to make contact with carers at some of the sites. In total we interviewed only 10 carers across seven of the 11 sites. In only one site were carers apparently receiving support for their role as carers; a carers' support group had been established in one of the TC services. Carers at this site appreciated the educational and information-giving aspects of the group as well as the mutual support they had found there. They had been offered the option of continuing with the group as a support group once the educational sessions had finished, and were optimistic about doing so.

Carers, friends and family members were sometimes mentioned by service users in connection with helping to make the decision to start attending a service, and with noticing changes in themselves some time later.

> We were taken into the quiet room and it was very informal, extremely friendly… and my husband was quite impressed because he was made very welcome. (SU6)

Most, although not all, of the carers expressed the wish for more support in the form of a support group or informal opportunity to meet other carers, as well as more information about the diagnosis of personality disorder. A key theme to emerge was the desire for ideas and suggestions about how to help their partner or family member, as part of the information about the diagnosis and how to manage it:

> To make [carers] part of the healing process, to involve them at times in the actual therapy itself, because it gives you a greater understanding on how to help your wife or whoever you're caring for. (CARER1)

A couple of people expressed reservations about asking for more support as it made them feel selfish, but there was little doubt they would have appreciated it. A few carers felt they could be more involved in the service itself, attending meetings with the service user, if the latter wished it. A couple of carers felt quite strongly that they should receive more information about the care and treatment received by their family member.

Service users in several services also felt that carers needed to be offered more support.

> If there was to be a monthly carers' group they could see what the [service] actually offers and [staff] could explain a bit more about the diagnosis and what to expect. (FGSU1-7)

> Sometimes you haven't got the opportunity to talk to people who know anything about it… just being able to talk is a very powerful thing. (CARER3)

Some carers were highly appreciative of the changes they had observed in their partners / family members and of the support they were receiving. One husband of a woman attending a TC service was pleased to see that she was engaging with the children more, and he had been able to relax more himself as a result. One of the positive outcomes mentioned by service users was improved relationships and interactions with other people in their lives, including family members, and this was borne out by the comments of some of the carers interviewed.

One carer, however, talked of feeling let down by the service at a time when his wife was going through a crisis. He felt support was withdrawn at a critical time and their daughter also became unwell. He was now finding it stressful having to deal with all of the agencies involved with both his wife and his daughter. He was critical that the pilot service did not involve him at an earlier stage, and felt that carers should be more involved in the care and treatment of their family members.

In another site, a carer said he was able to contact the service directly when concerned about his family member, and talk to a member of staff without the knowledge of the service user. In the same service, some ambivalence was expressed by a carer about the all-encompassing nature of the service; he felt somewhat excluded from what was going on for her.

Key messages from service users – carers

Few of the services had established support for carers; those that had were very much appreciated by the carers we interviewed.

Support for carers needs to make peer / mutual support available to carers, as well as providing information and education about the symptoms and problems associated with a personality disorder diagnosis.

4.3.10 Endings

There was not a great deal of discussion about endings, or leaving the services, in these interviews, as most services were relatively new and most of the service users were actively attending the service at the time. Nevertheless, some service users expressed anxieties about leaving, or being required to leave, before they felt ready to do so. For example, the service for young people had an age limit and one or two of the service users were anxious about hitting this age limit and having to leave before they felt ready.

Some of the past service users talked about how and why they had left the service. In one service, where we interviewed several past service users, the reasons given for leaving concerned aspects of the service itself. The past service users were critical of the rules regarding contact with other service users, and of the group work, and expressed the wish for access to individual therapy.

Some of the TC services had given serious consideration to endings, through setting up groups to prepare for leaving or groups for people who had left the community, which they could attend for a limited period. However, past service users in one service were critical of how this had happened. They felt they had had no involvement in the decisions made to end two different groups and described how members were 'devastated' and 'literally begging to keep it'. One or two said they were beginning to return to old patterns of behaviour, including self-harm, and were struggling to cope without the support of the group members and the facilitator.

> They decided [when the group would finish]. They did say that we have a say in it but we didn't. When we first started, they did say 'Oh, we'll see how it goes and you can tell us whether you want, you might want a few more, you might want a few less', that sort of thing, but when it actually came to it, it just suddenly became like it was fixed on 20 weeks and someone had decided that and that's how it was, you know. (SU55)

For these reasons, it was felt that the service should have a more structured approach to ending groups and that service users who have completed their treatment programmes should be able to retain some link with the service and / or the service users. There were plans to develop a self-help group for leavers and for those who were waiting to get on to the course or waiting to be referred to the service.

In one service, some people expressed concerns about the ending of therapy, although these had largely been allayed by the service in question offering a couple of people the opportunity to restart therapy if they found themselves to be in a crisis. However, one person did feel his therapy had ended quite abruptly with little opportunity to prepare for the ending. Another service user talked of trying to end therapy in collaboration with her therapist, but finding it too difficult to follow through. Another talked of reacting very badly to talking about ending therapy, and needing extra support. She had been reassured that she could remain in contact with other aspects of the service when therapy had ended. Despite preparing for ending therapy, it had somehow crept up on her:

> It just didn't seem real; I think that's one of my problems is until it happens, I can't grasp how it's going to feel and, I think, I don't know whether it was because therapy was coming to an end that things had got so much worse, but I hate to admit that because then they're probably right! (SU17)

Similarly, a past service user had concerns about the way in which the ending of therapy had been managed.

> I would have liked that to have gone on a bit longer, but it can't go on for five years, ten years, the rest of your life, can it?
>
> I: So how did that come to an end?
>
> It just stopped. We agreed, say, in a month's time that that would come to an end and it did. I think at the time I was a bit upset. You know… It was loads and then all of a sudden nothing. (SU16)

A couple of the pilot services with different service models had preferred not to place time limits on people's contact with the service. The peer support network, for example, did not feel the need to do so. Another service wished to remain as a long-term safety net for people; one service user described wanting to leave and being persuaded to stay or, at least, to remain registered with the service.

> Key messages from service users – endings
>
> People need clear information about, and careful preparation for, endings.
>
> Careful consideration needs to be given about how people can access services in the future following the end of their contact with dedicated teams.

4.3.11 Suggestions for service improvements

The following points are based on the suggestions for improvements made by the service users themselves:

- One clear theme to emerge concerned a need to improve the initial assessment process, primarily to ensure that people in future receive more support to assist them through the process. This suggestion was made in a number of services where the assessment and induction procedures were lengthy and involved a series of interviews as well as questionnaires to complete.

- Another key suggestion for improvement emerged from most of the TC-style services. Many comments were made about the size of the different groups and the need to ensure an optimal group size for each group to be effective, but the strongest criticisms were made of the TC preparatory groups: Options Group, MAC group, TAC. Suggestions included that these early groups be smaller to ensure that people receive sufficient support, or that other support, such as telephone contact, be made available to people at this stage. At present, there was a strong feeling across several services that service users felt they were not getting enough support at this stage, and were anxious about talking about difficult issues for fear of being left with painful feelings at the end of the session.

- Another issue that emerged from a number of the sites, again primarily the TC-style services, was a need for greater flexibility in the rules and boundaries in place; examples given were the medication policy, and the boundaries enforced around peer relationships. In some services, the concern was for the consistent application and interpretation of rules and boundaries.

- Flexibility as a theme continues into the next issue, which concerns the different therapeutic and other service options on offer at a service. Service users asked for more flexibility and choice, e.g. individual therapy at sites where only group therapy or peer support was on offer, and telephone contact or crisis support at sites where these were not currently available.

- In several sites, improvements to the information made available to service users and professionals to publicise the service were suggested. In some cases, this was more specifically targeted at the accessibility of the service.

- A number of concerns were raised in rural sites about the difficulties for some people in accessing the service, and suggestions were made about how to improve this through the hours of service, provision of transport or use of different venues.

- A related issue was the capacity of the services to respond to diversity; service users across different sites commented on this, and suggested that efforts be made to make contact with younger people, with people from black and minority communities and with more men. The issue of diversity in the service user group, however, also extended to the service's capacity to address the issues raised. In a couple of services it was suggested that staff needed more training, e.g. in group work, or that some practical factors, e.g. childcare, needed greater consideration by the service.

- Another suggestion to emerge from several sites was improved support for carers.

- Other suggestions for improvement included access to complementary therapies to be made available, a buddy scheme for service users new to the service, more user involvement in the service. Pleas were also made for better childcare support and access to benefits and housing advice.

5 Cohort study

Information about the size and funding of services, together with the demographic characteristics of the populations they serve are presented in Table 4. While several pilots provided services on more than one site, two included components that were managed separately and delivered very different interventions. At site one, funding was provided for brief primary care-based intervention and a separate, voluntary sector-based skills development service. At site four an outpatient service delivering a range of psychosocial interventions was funded alongside a case-consultation service that served a separate catchment area. Data from these components of the two pilots are presented separately.

Data on referrals and assessments were collected from all 11 pilots over variable periods of time between January 2004 and October 2006, ranging from six months to 27 months. Reasons for this variation include the stage of development of the service at the start of the study – some had not started providing direct services by January 2004, the way in which data were collected, and the rate at which pilots received referrals.

We aimed to collect data from a consecutive sample of all referrals until we had information on 100 people.

5.1 Demographic and clinical characteristics

We obtained basic data on 1428 referrals to the 11 services. While data on a consecutive sample of referrals were obtained from seven of the 11 pilots, we estimate that at the remaining three data were collected on between 30% and 67% of all those referred (see Table 5 below). For the service with the smallest sample (30%), we compared the age and gender of the sample with the service's referrals as a whole to check if it was representative on these measures. The mean age of the sample was 36.2 (SD=11.0) and of the referral population 36.0 (SD=10.2). The proportion of males in the sample was smaller than the referral population at 25.0% compared to 31.0%. In all but one service – the information and counselling service for adolescents – the proportion of women referred was greater than the proportion of men. Women formed 65% of the sample as a whole (ranging from 49% to 79%). Mean age of those referred to the adolescent service was 20.2 years; at the 10 services for adults with PD, mean age was fairly consistent, ranging from 34.8 to 39.0 years. Data on ethnicity were collected by 10 services. Black and Minority Ethnic residents make up between 1% and 36% of the local populations that pilots serve. The proportion of BME service users referred to each of the pilots varied widely between 0% and 27%. At seven of the 11 pilots, the proportion of BME service users referred was lower than local population estimates. For three services the proportion of BME users referred was far lower than general population estimates. Data on previous contact with mental health services was collected on 1077 service users at 10 sites. The majority of service users had had previous contact with mental health services across all the pilots (ranging between 77.9% and 100%).

Source of referrals to the different pilots are presented in Table 6. Mental health services formed the main source of referral, with 16% of service users being referred by self or friend / family member. Reasons for referral are presented in Table 7. Mental distress was by far the most frequently stated reason for referral, and concerns about self-harm and substance misuse also frequently mentioned. Concerns about aggression, violence or risk to others were mentioned in fewer than 5% of referrals.

5.2 Assessment and service provision

Data are presented on assessment and service provision for only those service users whose assessment started before April 2006 (see Table 8). This is because we wanted to allow sufficient time to elapse between referral and the end of data collection, autumn 2006, to ensure we were describing a group for whom assessment would have been completed and decisions made about what services they were to receive.

The proportion of those referred to services that were taken on varied considerably between the services: ranging from 100% at one service (where, once someone made contact in person with the pilot, they were offered a service) to 31.3% at a service delivering structured psychological therapies. In comparing the characteristics, of those where referred to pilot services with those who actually engaged with them, we excluded data from three services: the service user network (in which all those who contacted the service in person were offered it), a case consultation service (in which direct services to service users were not provided at the time data were collected), and the service for adolescents (which we excluded because not all those referred had PD). Results of this comparison are presented in Table 9. Those referred to services were similar to those who received them, except that the latter were less likely to be male. Men made up 429 (33.5%) of referrals and 189 (27.2%) of those taken on by the services (difference in proportions=6.3%, χ^2=8.8, p=0.003). Reasons why people were not provided a service were often not stated, but among those that were, failure to take up repeated offers of assessment appointments, absence of PD, presence of ASPD and substance misuse problems were regularly mentioned. In Table 10 the length of time between referral, assessment and being taken on for services is presented. This varied substantially across the services. Data in this table need to be interpreted with caution as they refer to people taken on to different components of the services. Qualitative data from services suggested that the main reason for delayed assessment was that some service users failed to attend initial appointments but continued to be offered further assessments over a longer period of time.

5.3 Minimum dataset

Minimum dataset (MDS) data were not collected by the pilot that provided information and advice to adolescents, but some data were collected at all 10 pilots working with adults with PD. Data were collected on 457 (32.0%) of those referred to services. At those pilots where a range of services were provided, MDS data tended to be collected from those who were offered formal interventions such as psychological treatment, case management or a place in a day hospital or day-TC. Characteristics of those who were offered a service for whom we have and do not have data are compared in Table 12. It can be seen that ethnicity and the proportion of those who had been in contact with mental health services are similar, but those with MDS data were a little older and less likely to be male.

Interpretation of quantitative data was made more complicated by changes to original versions of questionnaires made by two of the services. At one, one item of the Social Function Questionnaire (SFQ) concerning the service user's sex life was dropped. At another the scale used to rate items on the SAP-AS and SFQ was altered slightly and total scores had to be recalculated (see Table 13).

Mean SAP-AS scores across the services ranged from 5.2 to 6.2, with between 92% and 100% of the sample receiving a score of three or more which indicates the likely presence of PD (Moran *et al*. 2003). The majority of the sample (90.9%) stated that they wanted to change something about their personality. The proportion who endorsed this statement was lower at the case management service than at other pilot services (difference in proportions=18.8%, χ^2=6.73, p=0.009).

High levels of social dysfunction were found across all 10 services. Almost half the total sample had attended an emergency department (ED) in the six months prior to data collection, with over 60% of those taken on by the team delivering psychological therapies to people with PD and co-morbid substance misuse having attended an ED during this period. Levels of contact with other types of health and social care were high, with 37% of the sample having spent time on an inpatient mental health unit during the previous six months. Levels of service utilisation tended to be lower among users of the voluntary sector-based skills development service than at other pilots: for instance eight (17.8%) of 45 of their service users reported having been admitted to hospital in the last six months compared to 133 (41.2%) of 323 taken on by other services (difference in proportions=23.3%, χ^2=9.13, p=0.003).

Levels of contact with criminal justice services were generally lower, with 6.5% of the total sample having been charged with an offence in the six months prior to data collection.

5.4 Additional data

Six services collected further clinical information, which is presented in Table 14. Levels of suicidal ideation and behaviour were high, with 70% having thought about ending their life during the previous 12 months, and 47.0% reporting they tried to end their life during this period. Levels of substance misuse were also high, with the proportion misusing drugs more than twice as high in the dual diagnosis service than at other sites where this information was collected. Mean score on the Mental Health Inventory was 29.8 (SD=18.5), with over 90% of the sample experiencing a level of mental distress suggestive of a mental disorder. Levels of satisfaction with services were generally lower than those reported among users of general mental health and psychology services (Shipley *et al*. 2000).

5.5 Self-referral

Information on source of referral was obtained from 1324 people referred to the 10 adult services for people with PD. Of those 197 (14.9%) were self-referrals and eight (0.6%) were from family or friends. In Table 15, the characteristics of those who were referred by self / family or friends are compared with those who were referred by a professional. People who self-referred were on average three years older. But apart from this there were very few differences between the groups, e.g. levels of personality disturbance and social functioning and service utilisation were similar.

5.6 Ending contact with services

By the end of the period of data collection 335 (44.4%) of 755 service users who started to use a service were no longer in contact with it (see Table 11). Approximately a third had completed an intervention, with the remainder having dropped out of contact from the service or left early for other reasons.

Characteristics of those who left the service early are compared with those who completed a package of care or remain in contact with services, in Table 16. This comparison was restricted to seven services. Data from the service user network, which remained open to most service users, and case-management service, which planned to work with people long term, the case consultation service, as data do not relate to direct service provision, and the young people, as not all had PD are excluded. BME service users were less likely to remain in contact or complete an intervention and the trend was for people who referred themselves to services to be more likely to remain in contact or complete an intervention. Marked variations were also seen between services, so 'site' was also an important predictor of whether the participant dropped out of contact with services (χ^2=58.3, p<0.001).

By the end of follow-up 328 (76.1%) of 431 white participants had either completed or were still in contact with services compared to 18 (50%) of BME participants. Binary logistic regression revealed that the association between ethnicity and likelihood of dropping out of contact with the service was independent of the potential confounding effect of age, gender, site and self-referral. A trend towards self-referral being associated with remaining in contact or completing an intervention also remained.

Table 4. Key to services

Number	Main interventions	Funding in 2006/07 (£)	Catchment area	Population	Proportion non-white (%)	Deprivation index*
1	1a – voluntary sector-based skills development service 1b – primary care workers (plus organisational consultancy)	373,000	Inner-city area of large city	374,000	26	6 to 19
2	Outpatient psychological treatments for people PD and substance misuse	353,000	Urban and suburban areas of large city	457,000	36	47 to 163
3	Peer support for adults with PD	283,000	Inner-city and suburban area of large city	580,000	9 to 16	128 to 301
4	4a Outpatient psychological treatments for adults with PD 4b Consultation service	544,000	City, towns and urban, suburban and rural areas	709,000	3 to 11	4a: 218 to 345 4b: 100
5	Support, advice, psychological therapies and crisis beds for adults with PD	524,000	Small city and surrounding area	334,000	1 to 4	103 to 217
6	Support and advice, and day-TC for adults with PD	947,000	Medium-sized city, towns and surrounding suburban and rural areas	2,050,000	8	144 to 347
7	Support and advice, psychotherapy and day-TC for adults with PD	1,011,000	Medium-sized city and surrounding area	310,000	15	7
8	Individual and group psychotherapy programme for adults with PD	908,000	Medium-sized city and surrounding area	301,000	16	64
9	Support and advice, internet-based peer support and a day-TC for adults with PD	437,000	Small city, town and surrounding semi-rural, rural areas	310,000	1	84 to 200
10	Care coordination, psychological therapies and advice for adults with PD	872,000	Large city and surrounding areas	715,000	8	68
11	Information and counselling for adolescents with personality disturbance	517,000	Medium-sized city and surrounding semi-rural, rural areas	370,000	1 to 2	76 to 227

Table 5. Demographic and clinical characteristics

Service	1		2	3	4		5	6	7	8	9	10	11	TOTAL
	1a	1b			4a	4b								
Total (estimate)	**98**	**76**	**163**	**162**	206	**77**	**130**	**426**	**108**	**161**	**127**	**96**	**201**	**2031**
CPR data - N **(% of total case list)**	**98** (100)	**76** (100)	**163** (100)	**100** (61.7)	**94** (45.6)	**48** (62.3)	**130** (100)	**128** (30.0)	**108** (100)	**161** (100)	**127** (100)	**96** (100)	**99** (49.3)	**1428** (70.3)
Dates during which CPR data collected	09/04 - 03/06	08/04 - 06/06	08/04 - 06/06	05/05 - 02/06	04/04 - 06/05	11/04 - 07/06	07/04 - 10/06	01/04 - 11/05	01/05 - 12/05	01/04 - 04/06	01/04 - 08/06	11/04 - 07/06	10/04 - 04/05	01/04 - 10/06
Sex - valid cases male – **N** (% of valid cases)	98 **47** (48.0)	75 **30** (40.0)	160 **78** (48.8)	100 **31** (31.0)	94 **35** (37.2)	48 **21** (43.8)	130 **31** (23.8)	128 **27** (21.1)	108 **33** (30.6)	161 **37** (23.0)	127 **49** (38.6)	96 **30** (31.3)	99 **51** (51.5)	1424 500 (35.1)
Age - valid cases Mean age (SD)	95 38.2 (10.2)	73 38.2 (11.9)	156 34.9 (9.5)	65 39.0 (9.8)	85 34.8 (9.1)	44 35.8 (8.8)	130 37.8 (10.5)	125 35.1 (10.2)	90 35.6 (8.9)	157 35.1 (10.5)	123 35.5 (10.1)	93 37.4 (9.3)	99 20.2 (2.4)	1335 35.2 (9.3)
< 24 - N (%)	**8** (8.4)	**9** (12.3)	**25** (16.0)	**3** (4.6)	**9** (10.6)	**4** (9.1)	**15** (11.5)	**26** (20.8)	**15** (16.7)	**31** (19.7)	**22** (17.9)	**10** (10.8)	**95** (96.0)	272 (20.4)
25-34 - N (%)	**27** (28.4)	**22** (30.1)	**55** (35.3)	**21** (32.3)	**30** (35.3)	**16** (36.4)	**34** (26.2)	**34** (27.2)	**23** (25.6)	**50** (31.8)	**38** (30.9)	**24** (25.0)	**4** (4.0)	378 (28.3)
35-44 - N (%)	**37** (38.9)	**20** (27.4)	**53** (34.0)	**22** (33.8)	**32** (37.6)	**19** (43.2)	**47** (36.2)	**43** (34.4)	**35** (38.9)	**42** (26.8)	**39** (31.7)	**38** (39.6)	**0** (0.0)	427 (32.0)
45-54 - N (%)	**15** (15.8)	**14** (19.2)	**18** (11.5)	**14** (21.5)	**12** (14.1)	**3** (6.8)	**27** (20.8)	**19** (15.2)	**16** (17.8)	**29** (18.5)	**19** (15.4)	**19** (19.8)	**0** (0.0)	205 (15.4)
> 55 – N (%)	**8** (8.4)	**8** (11.0)	**5** (3.2)	**5** (7.7)	**2** (2.4)	**2** (4.5)	**7** (5.4)	**3** (2.4)	**1** (1.1)	**5** (3.2)	**5** (4.1)	**2** (2.1)	**0** (0.0)	53 (4.0)
Ethnicity – valid cases	87	59	163	84	0	37	130	128	98	161	126	84	0	1157
White British - N (%)	**53** (60.9)	**32** (54.2)	**132** (81.0)	**68** (81.0)	-	**34** (91.9)	**122** (93.8)	**117** (91.4)	**93** (94.9)	**154** (95.7)	**121** (96.0)	**79** (94.0)	-	1005 (86.9)
White Other – N (%)	**12** (13.8)	**11** (18.6)	**7** (4.3)	**6** (7.1)	-	**3** (8.1)	**4** (3.1)	**7** (5.5)	**3** (3.1)	**3** (1.9)	**5** (4.0)	**1** (1.2)	-	62 (5.4)
Black and ethnic minority - N (%)	**22** (25.3)	**16** (27.1)	**24** (14.7)	**10** (11.9)	-	**0** (0.0)	**4** (3.1)	**4** (3.1)	**2** (2.0)	**4** (2.5)	**0** (0.0)	**4** (4.8)	-	90 (7.8)
Previous contact with mental health – valid cases	91	68	153	19	0	45	128	94	101	161	123	94	0	1077
Previous contact with mental health - N (%)	**81** (89.0)	**53** (77.9)	**135** (88.2)	**17** (89.5)	-	**44** (97.8)	**124** (96.9)	**91** (96.8)	**101** (100)	**161** (100)	**117** (95.1)	**93** (98.9)	-	**1017** (94.4)

Table 6. Source of referrals

Service	1		2	3	4		5	6	7	8	9	10	11	TOTAL
	1a	1b			4a	4b								
Sample size: CPR data	98	76	163	100	94	48	130	128	108	161	127	96	99	1428
Source of referral – valid cases	95	76	159	100	86	48	129	125	105	161	127	96	99	1406
Self/ family/ friend – N	11	3	0	100	0	0	60	24	3	0	3	0	17	221(15.7)
(% valid cases)	(11.6)	(3.9)	(0.0)	(100)	(0.0)	(0.0)	(46.5)	(19.2)	(2.9)	(0.0)	(2.4)	(0.0)	(17.2)	
Secondary care – N	61	0	107	0	64	47	53	88	90	159	110	85	32	896(63.7)
(%)	(64.2)	(0.0)	(67.3)	(0.0)	(74.4)	(97.9)	(41.1)	(70.4)	(85.7)	(98.8)	(86.6)	(88.5)	(32.3)	
Social care – N	2	0	11	0	1	0	2	2	5	0	3	3	4	33(2.3)
(%)	(2.1)	(0.0)	(6.9)	(0.0)	(1.2)	(0.0)	(1.6)	(1.6)	(4.8)	(0.0)	(2.4)	(3.1)	(4.0)	
GP/primary care – N	7	73	2	0	17	1	4	6	4	2	7	0	11	134(9.5)
(%)	(7.4)	(96.1)	(1.3)	(0.0)	(19.8)	(2.1)	(3.1)	(4.8)	(3.8)	(1.2)	(5.5)	(0.0)	(11.1)	
Non-statutory – N	9	0	0	0	2	0	8	2	0	0	0	0	35	56
(%)	(9.5)	(0.0)	(0.0)	(0.0)	(2.3)	(0.0)	(6.2)	(1.6)	(0.0)	(0.0)	(0)	(0.0)	(35.4)	(4.0)
Drug & Alcohol – N	2	0	34	0	0	0	0	1	2	0	2	0	0	41(2.9)
(%)	(2.1)	(0.0)	(21.4)	(0.0)	(0.0)	(0.0)	(0.0)	(0.8)	(1.9)	(0.0)	(1.6)	(0.0)	(0.0)	
Criminal justice – N	3	0	6	0	2	0	2	0	1	0	2	8	1	25(1.8)
(%)	(3.1)	(0.0)	(3.8)	(0.0)	(2.4)	(0.0)	(1.6)	(0.0)	(1.0)	(0.0)	(1.6)	(8.3)	(1.0)	

Table 7. Reasons for referral*

Service	1		2	3	4		5	6	7	8	9	10	11	TOTAL
	1a	1b			4a	4b								
Sample size: CPR data	98	76	163	100	94	48	130	128	108	161	127	96	99	949
Number of valid cases	93	75	154	0	0	28	130	0	45	0	122	95	99	841
Harm to self/suicidal ideation – N (% valid cases)	10	2	37	–	–	12	54	–	10	–	73	55	131	384
	(4.4)	(1.1)	(6.8)			(15.2)	(25.0)		(16.1)		(18.5)	(20.1)	(44.3)	(16.8)
Harm to others/aggression/ offending – N (%)	7	10	38	–	–	3	11	–	3	–	27	9	4	112
	(3.1)	(5.4)	(6.9)			(3.8)	(5.1)		(4.8)		(6.8)	(3.3)	(1.4)	(4.9)
Eating Problems – N (%)	5	5	4	–	–	3	5	–	1	–	10	6	5	44
	(2.2)	(2.7)	(0.7)			(3.8)	(2.3)		(1.6)		(2.5)	(2.2)	(1.7)	(1.9)
Substance misuse – N (%)	13	6	106	–	–	10	17	–	2	–	29	27	53	263
	(5.7)	(3.2)	(19.3)			(12.7)	(7.9)		(3.2)		(7.3)	(9.9)	(17.9)	(11.5)
Higher use of other services – N (%)	0	0	0	–	–	2	7	–	0	–	9	9	32	59
	(0.0)	(0.0)	(0.0)			(2.5)	(3.2)		(0.0)		(2.3)	(3.3)	(10.8)	(2.6)
Mental distress – N (%)	96	78	102	–	–	21	97	–	10	–	102	39	14	559
	(42.3)	(41.9)	(18.6)			(26.6)	(44.9)		(16.1)		(25.8)	(14.2)	(4.7)	(24.5)
Coping and social – N (%)	40	29	156	–	–	2	7	–	9	–	34	26	10	313
	(17.6)	(15.6)	(28.5)			(2.5)	(3.2)		(14.5)		(8.6)	(9.5)	(3.4)	(13.7)
Relationship problems – N (%)	8	23	30	–	–	3	0	–	1	–	36	2	40	143
	(3.5)	(12.4)	(5.5)			(3.8)	(0.0)		(1.6)		(9.1)	(0.7)	(13.5)	(6.3)
History of abuse/PTSD/ trauma – N (%)	4	5	3	–	–	4	2	–	0	–	6	10	2	36
	(1.8)	(2.7)	(0.5)			(5.1)	(0.9)		(0.0)		(1.5)	(3.6)	(0.7)	(1.6)
Homelessness – N (%)	0	8	3	–	–	1	0	–	18	–	0	1	0	31
	(0.0)	(4.3)	(0.5)			(1.3)	(0.0)		(29.0)		(0.0)	(0.4)	(0.0)	(1.4)
Diagnosis of PD – N (%)	19	8	22	–	–	7	11	–	0	–	43	64	0	174
	(8.4)	(4.3)	(4.0)			(8.9)	(5.1)		(0.0)		(10.9)	(23.4)	(0.0)	(7.6)
Impulsiveness – N (%)	2	1	27	–	–	0	0	–	1	–	10	6	1	48
	(0.9)	(0.5)	(4.9)			(0.0)	(0.0)		(1.6)		(2.5)	(2.2)	(0.3)	(2.1)
Learning difficulties – N (%)	1	1	0	–	–	1	0	–	0	–	0	9	0	12
	(0.4)	(0.5)	(0.0)			(1.3)	(0.0)		(0.0)		(0.0)	(3.3)	(0.0)	(0.5)
Psychotic symptoms – N (%)	12	3	13	–	–	8	0	–	2	–	5	1	3	47
	(5.3)	(1.6)	(2.4)			(10.1)	(0.0)		(3.2)		(1.3)	(0.4)	(1.0)	(2.1)
Physical problems – N (%)	2	6	1	–	–	0	2	–	0	–	5	1	0	17
	(0.9)	(3.2)	(0.2)			(0.0)	(0.9)		(0.0)		(1.3)	(0.4)	(0.0)	(0.7)
Other – N (%)	8	1	6	–	–	2	3	–	5	–	6	9	1	41
	(3.5)	(0.5)	(1.1)			(2.5)	(1.4)		(8.1)		(1.5)	(3.3)	(0.3)	(1.8)

Table 8. Assessment and offer of services (NB tables from here on include those referred into the services in or before April 2006)

Service	1		2	3	4		5	6	7	8	9	10	11	TOTAL
	1a	1b			4a	4b								
Sample size: CPR data	98	76	152	100	94	36	121	128	108	107	112	86	99	1317
Number offered assessment – **N** (% of valid cases)	94 (95.9)	73 (96.1)	120 (79.5)	100 (100)	94 (100)	33 (91.7)	121 (100)	124 (97.6)	108 (100)	98 (91.6)	99 (90.8)	46 (53.5)	84 (84.8)	1194 (90.7)
Attended assessment – **N** (% of those offered one)	69 (73.4)	61 (83.6)	105 (87.5)	100 (100)	93 (98.9)	29 (87.9)	120 (100)	117 (94.4)	88 (83.0)	95 (96.9)	69 (74.2)	40 (97.6)	79 (94.0)	1065 (89.2)
Met criteria – **N** (%)	67 (97.1)	60 (98.4)	82 (79.6)	100 (100)	47 (69.1)	29 (100)	120 (100)	117 (100)	84 (100)	69 (75.8)	64 (92.8)	34 (97.1)	69 (89.6)	942 (88.5)
Offered service – **N** (%)	57 (85.1)	57 (95.0)	59 (72.0)	100 (100)	47 (100)	27 (96.4)	120 (100)	106 (93.8)	84 (100)	63 (94.0)	47 (77.0)	31 (93.9)	69 (100)	867 (81.4)
Received a service – **N** (% of those offered a service)	53 (93.0)	45 (78.9)	51 (86.4)	100 (100)	39 (88.6)	–	119 (99.2)	100 (95.2)	75 (98.7)	61 (100)	38 (100)	29 (100)	58 (84.1)	768 (88.6)
Received a service (% of those referred)	54.1	59.2	31.3	100	41.5	–	91.5	78.1	69.4	57.0	33.9	33.7	58.6	58.3

Table 9. Demographic and clinical characteristics of those referred to and using pilot services. (Excludes referrals to 3, 4b and 11)

Variable	Referrals (n = 1087)	Offered an assessment (n = 985)	Attended assessment (n = 866)	Offered a service (n = 681)	Started the service (n = 621)
Age – median (SD)	35.7 (9.9)	35.7(9.9)	35.7 (9.9)	36.2 (10.0)	36.1 (9.9)
Gender – male N (%)	371 (34.2)	324 (32.9)	274 (31.7)	194 (28.5)	170 (27.4)
Ethnicity – non-white N (%)	71 (6.5)	67 (6.8)	63 (7.3)	46 (6.8)	41 (6.6)
Previous contact with mental health services – N (%)	865 (94.1)	772 (93.9)	674 (93.9)	555 (93.8)	516 (94.5)

Table 10. Time interval (in days) between date of referral, assessment, start and end of treatment

Service	1		2	3	4		5	6	7	8	9	10	11
	1a	1b			4a	4b							
Median time from referral to assessment (range)	26 (0-139)	17.5 (3-107)	35.5 (1-520)	-	57 (0-280)	50 (17-148)	0 (0-259)	48 (0-259)	60 (6-209)	29 (0-384)	55 (0-383)	44 (15-280)	16.5 (0-324)
Median length of time from assessment to treatment (range)	18 (4-177)	1.5 (0-56)	63.5 (0-389)	-	175.5 (27-835)	41 (41-41)	0 (0-97)	49 (0-474)	26 (3-218)	40 (0-231)	63 (8-287)	153 (82-337)	5 (0-223)
Median length of time in treatment (range)	114 (0-515)	35 (0-400)	233 (3-765)	179 (0-389)	251 (156-356)	-	288 (44-804)	140 (0-647)	171.5 (1-346)	195 (47-487)	84 (18-337)	291.5 (121-462)	202 (0-602)

Table 11. Ending contact with services

Service	1		2	3	4		5	6	7	8	9	10	11	TOTAL
	1a	1b			4a	4b								
Number who received a service	**53**	**45**	**51**	**87**	**39**	**–**	**119**	**100**	**75**	**61**	**38**	**29**	**58**	**755**
Ended contact with service – **N** (% who received a service)	**35** (67.3)	**38** (84.4)	**21** (41.2)	**26** (29.9)	**15** (38.5)	**–**	**17** (14.3)	**55** (55.0)	**49** (65.3)	**15** (24.6)	**20** (52.6)	**2** (6.9)	**42** (72.4)	**335** (44.4)
Reasons for ending contact (valid cases – N)	34	38	18	–	15	–	17	55	49	12	19	2	41	300
Completed package of care – N (% of total who have ended contact)	**8** (23.5)	**23** (60.5)	**7** (33.3)	–	**1** (6.7)	–	**4** (22.2)	**27** (49.1)	**27** (55.1)	**5** (38.5)	**0** (0.0)	**0** (0.0)	**13** (31.0)	**115** (38.3)
Dropped out of contact – **N** (%)	**13** (38.2)	**6** (15.8)	**8** (38.1)	–	**2** (13.3)	–	**3** (16.7)	**12** (21.8)	**20** (40.8)	**5** (38.5)	**11** (57.9)	**1** (50.0)	**16** (38.1)	**97** (32.3)
Offered other service/ support* – **N** (%)	**1** (2.9)	**3** (7.9)	**0** (0.0)	–	**2** (13.3)	–	**0** (0.0)	**5** (9.0)	**0** (0.0)	**1** (7.7)	**0** (0.0)	**0** (0.0)	**1** (2.4)	**13** (4.3)
Client moved from area – **N** (%)	**2** (5.9)	**1** (2.6)	**2** (9.5)	–	**1** (6.7)	–	**4** (22.2)	**0** (0.0)	**0** (0.0)	**1** (7.7)	**0** (0.0)	**0** (0.0)	**6** (14.3)	**17** (5.7)
Disciplinary Reasons – **N** (%)	**0** (0.0)	**0** (0.0)	**0** (0.0)	–	**0** (0.0)	–	3 (16.7)	**0** (0.0)	**0** (0.0)	**0** (0.0)	**0** (0.0)	**0** (0.0)	**0** (0.0)	**3** (1.0)
Other – **N** (%)	**10** (29.4)	**5** (13.2)	**1** (4.8)	–	**9** (60.0)	–	3 (16.7)	**11** (20.0)	**2** (4.1)	**1** (7.7)	**8** (42.1)	**1** (50.0)	**5** (11.9)	**55** (18.7)

*Note: Many of those who completed packages of care or left for other reasons were also provided with information about other services

Table 12. Comparison of characteristics of those with minimum dataset data and those without

	Minimum data set	No minimum data set	Difference
Age (n = 1341) (SD)	36.2 (10.0)	34.5 (10.7)	1.7 (p = 0.01)
Gender (n = 1341) – male N (%)	114 (28.6)	388 (37.6)	– 9.0 (p = 0.01)
Ethnicity (n = 1111) – non-white N (%)	23 (6.3%)	53 (7.1%)	0.8 (p= 0.595)
Previous contact with mental health services (n = 1088) – N (%)	330 (93.2)	697 (95.0)	1.8 (p = 0.261)

Table 13. Baseline clinical data from the minimum dataset (MDS)

Service	1		2	3	4		5	6	7	8	9	10	11	TOTAL
	1a	1b			4a	4b								
Sample size: MDS data – N (%)	45	11	57	42	39	29	53	88	25	23	23	22	0	457
SAPAS – valid cases	36	9	53	33	29	19	49	76	19	23	21	22		389
Mean SAP-AS score (SD)	5.3	6.2	5.4	5.3	5.8	5.5	5.2	5.3	6.0	6.0**	5.7	5.3	-	5.6
	(1.6)	(1.3)	(1.5)	(1.6)	(2.0)	(1.8)	(1.7)	(1.7)	(1.4)	(1.3)	(1.5)	(1.3)		(1.6)
Proportion scoring ≥ 3.00	34	9	50	32	27	18	46	70	19	23**	20	21	-	369
	(94.4)	(100)	(94.3)	(97.0)	(93.1)	(94.7)	(93.9)	(92.1)	(100)	(100)	(95.2)	(95.5)		(94.9)
Type R/S – valid cases	45	10	55	39	34	23	51	83	23	22	23	22		430
Treatment seeking – N (% of valid cases)	38	10	50	38	31	20	44	77	22	22**	23	16	-	391
	(84.4)	(100)	(90.9)	(97.4)	(91.2)	(87.0)	(86.3)	(92.8)	(95.7)	(100)	(100)	(72.7)		(90.9)
Six month service utilisation - valid cases	45	–	52–56	–	36–38	29	51–53	82-84	24	21–22	20–23	–	–	360–374
Emergency contact with GP – N (%)	14	–	6	–	23	12	28	49	12	11	14	–	–	169
	(31.1)		(11.1)		(63.9)	(41.4)	(53.8)	(59.8)	(50.0)	(50.0)	(60.9)			(44.2)
Attendance at A&E – N (%)	12	–	32	–	18	14	29	36	14	12	12	–	–	179
	(26.7)		(60.4)		(47.4)	(48.3)	(54.7)	(42.9)	(58.3)	(54.5)	(57.1)			(47.2)
Admission to hospital – N (%)	8	–	17	–	17	14	22	35	11	11	6	–	–	141
	(17.8)		(32.7)		(44.7)	(48.3)	(42.3)	(42.7)	(45.8)	(50.0)	(30.0)			(37.3)
Contact social services – N (%)	17	–	21	–	15	17	22	34	12	7	11	–	–	156
	(37.8)		(38.9)		(40.5)	(58.6)	(42.3)	(40.5)	(50.0)	(33.3)	(52.4)			(40.9)
Contact with police – N (%)	9	–	15	–	8	6	14	24	6	6	8	–	–	96
	(20.0)		(26.8)		(21.6)	(20.7)	(27.5)	(28.9)	(25.0)	(27.3)	(36.4)			(25.1)
Charged with an offence – N (%)	4	–	4	–	3	1	3	5	1	2	2	–	–	25
	(8.9)		(7.1)		(8.1)	(3.4)	(5.7)	(6.0)	(4.2)	(9.1)	(9.1)			(6.5)
Social functioning – valid cases	44	–	44	31	23	21	44	78	22	21	19	18	–	365
Mean social function (SD)	11.4 *	–	15.0	14.1	14.5	17.3	13.7	14.1	16.1	11.7**	14.1	12.6	–	14.1
	(3.2)		(4.1)	(3.5)	(5.2)	(4.2)	(4.9)	(3.9)	(3.6)	(3.8)	(4.6)	(4.1)		(4.1)

*11 items only **Transformed data

Table 14. Additional Items

Service	2	3	4		6	7	9	11	TOTAL
			4a	4b					
Sample size: MDS data – N (%)	57	42	39	29	88	25	23	22	325
Suicidal ideation and behaviour – valid cases	55–56	–	38–39	29	81-82	24	22	–	249–252
Proportion thinking life is not worth living in the previous week – N (%)	17 (30.4)	–	16 (41.0)	17 (58.6)	40 (48.8)	16 (66.7)	11 (50.0)	–	117(45.5)
Proportion thinking life is not worth living in the previous year – N (%)	43 (76.8)	–	34 (87.2)	24 (82.8)	66 (80.5)	23 (95.8)	18 (81.8)	–	208 (80.9)
Proportion who thought of ending life in last week – N (%)	13 (23.6)	–	15 (38.5)	15 (51.7)	36 (43.9)	13 (54.2)	10 (45.5)	–	102 (39.8)
Proportion who thought of ending life in last year – N (%)	27 (72.7)	–	32 (82.1)	23 (79.3)	60 (73.2)	21 (87.5)	16 (72.7)	–	179 (69.9)
Proportion who attempted to take life in last week – N (%)	0 (0.0)	–	2 (5.3)	5 (17.2)	2 (2.5)	1 (4.2)	1 (4.5)	–	11 (4.3)
Proportion who attempted to take life in last year – N (%)	27 (50.0)	–	18 (47.4)	15 (51.7)	37 (45.7)	13 (54.2)	9 (40.9)	–	119 (47.0)
Drug and Alcohol Use – valid cases	34-56	–	33-39	28-29	80-88	23-24	22	–	220-258
Excessive alcohol use in the last month – N (%)	33 (58.9)	–	9 (23.1)	10 (35.7)	23 (28.0)	7 (30.4)	8 (36.4)	–	90 (35.3)
Excessive alcohol daily/almost daily – N (%)	10 (17.9)	–	1 (2.6)	5 (17.9)	4 (4.9)	3 (13.0)	2 (9.1)	–	25 (9.8)
Used cannabis in the last 3 months – N (%)	12 (35.3)	–	7 (21.2)	5 (17.8)	19 (23.8)	4 (17.4)	4 (18.2)	–	51 (22.7)
Used stimulant substances in the last 3 months – N (%)	9 (17.3)	–	4 (10.8)	1 (3.4)	5 (5.7)	2 (8.3)	1 (4.3)	–	22 (9.4)
Used opiates in the last 3 months – N (%)	3 (5.8)	–	1 (2.7)	1 (3.4)	0 (0.0)	0 (0.0)	2 (8.7)	–	7 (3.0)
Therapeutic alliance – valid cases	44	29	20	24	65	21	20	20	243
Therapeutic alliance – Mean (SD)	19.0 (2.8)	19.7 (4.6)	19.9 (5.6)	19.2 (6.0)	20.7 (5.5)	20.4 (7.3)	22.2 (4.6)	22.5 (6.7)	20.5 (5.4)
Mental Health Inventory – valid cases	55	–	33	27	76	24	22	–	237
Mental Health Inventory – Mean (SD)	28.5 (17.6)	–	29.7 (18.0)	24.6 (21.0)	36.4 (19.3)	25.8 (16.3)	33.8 (19.0)	–	29.8 (18.5)
Mental Health Inventory – Proportion scoring <60.4 – N (%)	53 (96.4)	–	31 (93.9)	25 (92.6)	66 (86.8)	24 (100)	19 (86.4)	–	218 (92.0)
Satisfaction – valid cases	50	–	20	20	55	21	22	–	188
Satisfaction – Mean (SD)	11.2 (1.7)	–	7.3 (2.9)	7.8 (4.1)	8.6 (2.2)	5.7 (3.6)	8.2 (2.9)	–	8.1 (2.9)

Table 15. Characteristics of self-referrals* and those referred by professionals

Variable	Self-referral*	Referred by professionals	Difference in proportions
Age (N = 1236) S.D	38.9 (10.0)	35.9 (10.0)	3.0 (p <0.001)
Gender (N = 1320) Male n (%)	60 (41.6%)	387 (53.0%)	- 11.4 (p = 0.17)
Ethnicity (N = 1010) Non-white n (%)	14 (9.8%)	61 (7.0%)	2.8 (p = 0.32)
Previous contact with mental health services (N = 1076) n (%)	6 (5.0%)	54 (5.6%)	-0.6 (p=0.95)
SAP-AS score (N =345) Mean (SD)	5.3 (1.5)	5.5 (1.6)	0.2 (p = 0.33)
Proportion who want to change something in their personality (N=376) n (%)	58 (90.6%)	282 (90.4%)	0.2 (p=1.00)
Social Function Questionnaire (N = 305) Mean (SD)	14.0 (4.0)	14.1 (4.3)	-0.1 (p = 0.93)
Proportion attended AED in last 6 months (N = 319) n (%)	17 (50.0)	143 (50.2)	-0.2 (p = 1.00)
Proportion admitted to hospital in last 6 months (N = 312) n (%)	12 (36.4%)	108 (38.7%)	-2.3 (p=0.942)
Proportion charged with an offence (N = 325) n (%)	1 (2.9%)	21 (7.2%)	-4.3 (p=0.563)

*Includes 8 people who were initially referred by family and friends

Table 16. Comparison of characteristics of those who remain in contact with services or completed an intervention to those who left prior to completion

Variable	Completed or still in service	Left prior to completion	Difference in proportions or means
Age (N = 516) Mean (SD)	36.6 (9.9)	35.2 (10.2)	1.4 (p = 0.17)
Gender (N = 538) Male – n (%)	99 (25.2)	47 (32.4)	-7.2 (p = 0.118)
Ethnicity (N = 467) non white – n (%)	30 (6.4)	17 (12.0)	-4.0 (p = 0.046)
Previous contact with mental health services (N = 467) n (%)	333 (95.1)	107 (91.5)	3.6 (p = 0.211)
Self referral (N =529) n (%)	69 (17.7)	15 (10.7)	7.0 (p = 0.07)
SAP-AS score (N =224) Mean (SD)	5.4 (1.5)	5.7 (1.6)	-0.3 (p = 0.19)
Proportion who want to change something in their personality (N=235) – n (%)	158 (89.8)	54 (91.5)	-1.7 (p = 0.889)
Social Function Questionnaire (N =194) Mean (SD)	14.0 (4.4)	14.2 (3.9)	-0.2 (p = 0.73)
Proportion attended AED in last 6 months (N = 229) n (%)	84 (48.8)	26 (45.6)	3.2 (p = 0.788)
Proportion admitted to hospital in last 6 months (N = 223) n (%)	58 (34.5)	23 (41.8)	-7.3 (p = 0.415)
Proportion charged with an offence (N =232) n (%)	8 (4.6%)	6 (10.5%)	-5.9 (p = 0.187)

6 Delphi study

6.1 Response rate

Eighty-eight people (88.9%) responded to the first-round questionnaire. The response rate was greater among service providers than among the other two groups (87.1% expert authors, 97.1% providers and 82.4% of service users responded).The response rate in round two was 84.8% (83.9% of expert authors, 91.2% of service providers and 79.4% of service users), and 81.8% in round three (74.2% of expert authors, 79.4% of providers and 88.2% of service users).

Delphi respondents who were service providers or expert authors came from a range of backgrounds and used a variety of approaches to working with people with PD. Respondents were able to indicate more than one background or therapeutic approach, e.g. psychiatrist and psychotherapist / Therapeutic Community and psychodynamic psychotherapy etc. Twenty-one (33.9%) respondents stated that their professional background was in psychiatry, 13 (21%) in psychology, 12 (19.4%) in psychotherapy, eight (12.9%) in nursing and two (3.2%) in social work. Fifty-seven (91.9%) respondents provided information on their main therapeutic approach. The most frequently reported of these were psychodynamic psychotherapy (N=17, 29.8%), therapeutic community (N=13, 22.8%), DBT (N=8, 14.0%) and CBT (N=8, 14.0%).

6.2 Consensus items

Consensus was reached on ten items in round one, five items in round two and six items in round three. Items on which consensus was reached are listed in Table 17 below. A detailed breakdown of items that reached consensus among each of the three stakeholder groups is presented in Appendix 4. Each group reached consensus on 19 items, with 10 items reaching consensus level among all three stakeholder groups.

The item that attracted the lowest degree of consensus was*:* 'It does not matter if PD services do not have a clear treatment model, as long as there are demonstrable positive outcomes for service users and others', which was supported by 25% of respondents and opposed by 36%, with the remaining 39% neither supporting nor opposing the item. For seven other items fewer than 50% of participants fell into any of these three groups. These were:

- ▪Dedicated services should use assertive outreach in order to work with people with severe PD who do not attend their appointments (41% supported this statement).

- Dedicated PD services should provide service users some form of access to their own staff 24 hours a day (39% opposed this statement, 40% were neutral).

- Dedicated services for people with PD should help service users reduce, with a view to stopping, using psychiatric medication (40% supported the statement, 49% were neutral).

- When people with PD have significant housing or social problems these need to be addressed before the start of psychological treatment (39% supported this statement, 47% were neutral).

- People with personality disorder usually need to be seen at home for at least one occasion to enable a full assessment of their problem and its likely treatment to be made (34% opposed this statement, 41% were neutral).

- Service users should be encouraged and supported to run out-of-hours crisis support (38% supported this statement, 49% were neutral).

- All people with PD should have access to user-led services (43% supported this statement).

Differences also emerged between expert authors and service providers from different professional and therapeutic backgrounds. These included:

- People from a psychodynamic psychotherapy background are more likely to disagree with the statement that people with PD should be treated in the community under powers of the Mental Health Act (77.8% of people from this background disagreed with this statement compared to 55.6% overall)

- Psychiatrists were more likely to endorse the statement that dedicated teams should have regular input from a psychiatrist (88.9% of psychiatrists endorsed this statement compared to 50.0% of psychologists and 58.6% of service users)

- Psychologists were more likely than psychiatrists to **disagree** that it does not matter if there is a clear treatment model in place as long as the outcomes are positive (80% of psychologists compared with 38.9% of psychiatrists)

- People from a CBT background are more likely than others to **disagree** with the statement that services should NOT be expected to work with people with a history of violent offending. (75% of people from a CBT background, compared with 60.5% overall)

- All people from a DBT background agreed that there should be input in a dedicated team from a service user worker (100% of people from a DBT background, compared with 81.3% overall)

- People from a therapeutic community background were more likely to agree with statements about peer support (91.7% compared with 66.7% overall), peer enforced sanctions (100% compared with 61.7% overall) and peer run out-of-hours support (75% compared with 37.0% overall) than other participants.

6.3 Ranking items

Priorities for service development were rated by all 88 people who responded to the first-round questionnaire. Top rating items in each of the three groups and for the group as a whole are presented in Table 18. Responses of all three stakeholder groups were similar, with four services scoring consistently highly:

- a service which aims to reduce stigma and discrimination

- a community-based service providing psychological treatments

- dedicated day service

- a consultation service providing expert guidance.

Two types of service – therapeutic communities and inpatient units for people with severe PD – were rated as not being high priorities by all three stakeholder groups.

Preferences for outcome measures for services are presented in Table 19. All measures scored highly and differences between the six items were not great. Quality of life was ranked highest across all three groups. Expert authors and service providers placed social function as the next most important outcome, with service users opting for symptoms of mental distress. User satisfaction with quality of care was rated the least important outcome measure by all three stakeholder groups, but even this measure received a median rating of 7.0.

Table 17. Items reaching consensus

Item No.	Statement	Round when consensus was reached
1.1	Most people with PD require dedicated services to help them cope with their problems.	R3
1.10	Dedicated PD teams should provide services for people who have PD and sometimes hear voices or experience other psychotic symptoms.	R1
1.12	Dedicated PD services should be open to self-referral.	R3
1.13	When mental health services refer someone to a dedicated PD service it is important for a member of the referring team to remain in regular contact with them.	R3
1.14	It is unacceptable for community mental health teams to have a policy of NOT working with people with a primary diagnosis of PD.	R2
2.3	Interventions aimed at helping people with PD develop better coping strategies need be delivered over years not months.	R1
2.4	Services for people with PD should provide care coordination under the 'care programme approach' (CPA).	R3
2.5	Care plans with short- and long-term treatment goals agreed by the client are important if progress in treatment is to be both achieved and recognised.	R1
2.7	Dedicated services for people with PD should be able to arrange more intensive support at times of crisis such as home treatment or residential care.	R1
2.8	Limits on the availability of staff and other boundaries need to be made clear to service users at the start of treatment and stuck to throughout treatment	R1
2.9	Responsibility for client welfare should be shared by a team and/or the community, rather than by individual staff members.	R1
2.11	Some PD clients cannot cope with groups or environments where people have to interact.	R1
2.13	Risk management for people with PD involves placing a high degree of choice and responsibility with the person who is harming her/himself.	R1
2.15	Services for people with PD should try to obtain users' consent to contact, support and inform carers.	R2
2.18	Users and their carers should be involved in making decisions about service development.	R1
3.1	The personal qualities of staff – such as self-awareness and ability to observe boundaries – are more relevant to working well with PD clients than professional qualifications.	R2
3.2	Teams delivering services to people with PD need to consist of people with a range of professional and non-professional backgrounds.	R2
3.5	Teams delivering services for people with PD should have regular input from an 'expert by experience' (a service-user worker).	R3
3.6	It is essential for staff of PD services to have a forum to come together to reflect on their practice, their relationships with clients and the impact their work has on team members.	R1
3.8	Training in this field should ideally be given to teams, rather than individuals.	R2
4.5	Service users are able to successfully run groups for people with PD as long as they are provided with training and support.	R3

Table 18. Priorities for service development

Rank order	Service development priorities	Expert author Median (mean)	Service Provider Median (mean)	Service user Median (mean)	TOTAL Median (mean)
1	A service which aims to reduce stigma and discrimination	7.0 (6.3)	8.0 (7.7)	9.0 (8.0)	8.0 (7.4)
1	A community-based service providing psychological treatments	7.0 (6.8)	7.0 (7.2)	8.0 (8.1)	8.0 (7.4)
3	Dedicated day service	7.0 (6.9)	7.0 (7.0)	8.0 (7.4)	7.0 (7.1)
3	A consultation service providing expert guidance	7.0 (6.5)	7.0 (7.4)	7.5 (7.4)	7.0 (7.1)
5	Training and support to enable people to get back into employment	7.0 (6.8)	7.0 (7.3)	6.0 (6.3)	7.0 (6.8)
5	Organisational change and service developments to non-specialist services	6.0 (6.4)	7.0 (7.1)	7.0 (6.8)	7.0 (6.8)
7	A dedicated case-management team	7.0 (6.5)	6.0 (6.2)	7.0 (7.1)	7.0 (6.6)
8	Deployment of dedicated PD workers working within existing CMHTs	5.0 (5.6)	7.0 (6.1)	7.0 (7.1)	7.0 (6.2)
9	A service user network	5.0 (5.4)	7.0 (6.8)	7.0 (6.5)	6.0 (6.3)
10	A therapeutic community	4.0 (4.6)	5.0 (5.6)	6.5 (5.7)	5.0 (5.3)
11	An inpatient unit for people with severe PD	4.0 (4.3)	5.0 (4.8)	5.5 (5.8)	5.0 (5.0)

Table 19. Preferred measures of service outcomes

Outcome measure	Expert authors	Service Providers	Service users	Total
Improved quality of life (a person's level of comfort, enjoyment, and ability to pursue daily activities) to normal levels	8.0 (7.5)	8.0 (8.0)	8.0 (7.8)	8.0 (7.8)
Improved social functioning (e.g. so people can sustain long-term relationships in their work and personal life)	7.0 (7.6)	8.0 (8.2)	7.5 (7.5)	8.0 (7.8)
Reductions in impulsive behaviour so that self-harming, aggression and/ or violence stops	7.0 (7.3)	7.0 (7.4)	8.0 (7.0)	7.0 (7.3)
Reductions in symptoms of anxiety, depression and mental distress to normal levels	7.0 (6.7)	7.0 (6.9)	8.0 (7.6)	7.0 (7.0)
Reduced levels of use of inpatient care and contacts with emergency medical services	7.0 (6.7)	7.0 (6.9)	7.0 (6.8)	7.0 (6.8)
User-rated satisfaction with service quality	6.0 (6.1)	7.0 (6.6)	7.5 (6.8)	7.0 (6.5)

7 Discussion

In this section we summarise our findings and examine study limitations before considering implications of the study for commissioners, providers and users of services for people with PD.

7.1 Overview of study findings

7.1.1 Case studies and overarching themes

The case studies provide a detailed picture of the first phase of the development of the 11 pilot services. By spring 2007 all of the pilot services were operational, working with people with PD and liaising with colleagues in other services. The speed with which pilots developed varied considerably and reflected differences in the extent of services already working with client groups prior to the start of funding as well as problems faced by some pilots in recruiting staff and identifying suitable premises. Many of the challenges faced in setting up pilot services were generic to setting up any new service. Other challenges were more specifically related to setting up dedicated community-based services for people with PD. For instance, service leads did not have a workforce with the skills needed to undertake this work and often had to train new team members to deliver psychological interventions and provide practical help and support; services that delivered interventions that relied on group work and peer support needed additional time to develop.

While the range of approaches to providing services detailed in the original plans for the pilots varied greatly, there was a degree of convergence in the content of interventions that were subsequently delivered. Services which originally planned to place a greater emphasis on direct service provision found that limited capacity to deliver this meant training and support for other service providers became a larger part of their work. Pilots that initially placed greater emphasis on indirect service provision found direct work with people with PD helped build relationships with local referrers and increased the credibility and valued attached to their efforts to support and train mainstream staff. Several services expanded the range of different interventions they originally planned to offer. This provided a way of increasing the numbers of people that pilots could work with, but was also done in an effort to promote autonomy and choice, and in response to the broad range of needs and abilities that people referred to services presented with. Staff at pilot sites repeatedly told us that 'one size does not fit all'.

Many of the service users we interviewed had previous experiences of feeling rejected by health and social care services, and spoke of the relief and hope they experienced on finding out there was a service that had been specifically designed to try to help them. These feelings were accompanied by concerns about would happen if their contact with the pilot service did not work out or came to an end. Service users felt that referral to a dedicated PD service was a 'last chance' to get help and support.

Service users appreciated the flexible and welcoming approach of staff and the relative ease with which they were able to access services. The outcomes discussed by service users were largely positive and constructive. Most service users spoke of positive changes in the way they felt about themselves and related to others. Negative or insignificant outcomes were mentioned by only a few. Service users appreciated staff at the pilots for being sincere, for their acceptance of people and non-judgemental approach, for offering their support and knowledge, and for treating service users with respect.

Staff working in general health and social care told us that pilot services were valuable because general services lacked the time and skills needed to help people with PD. Some told us that existing services were sometimes unhelpful and that the development of dedicated services for people with PD had helped to challenge the notion there was nothing that could be done to help people with these problems. Some referrers were disappointed to find dedicated services were unable to work with people who were very chaotic or not sufficiently psychologically minded. Staff who had received tier one interventions welcomed this aspect of the work of dedicated services. Opinions were divided about the optimal content of such interventions, with some preferring general training on PD treatment approaches, while others found specific case consultations on specific cases more useful.

The commissioners we interviewed had generally been involved in setting up pilot services and were also positive about them. They told us that gaps in the service concerning PD had been signalled by service users and carers. However they expressed concerns about the small numbers which some services had taken on, and were keen for others to expand the geographical area that they currently cover. Commissioners felt that PD services should become more integrated with other services such as primary care and criminal justice services. Some warned that services for people with PD were not a national service priority and told us that, without ring-fenced funding, pilot services would need to be able to demonstrate that they reduced use of other services, particularly out-of-area placements and inpatient mental health services.

7.1.2 Cohort study

Pilot services received a large number of referrals of people with PD. As with reports from other treatment services, people referred to pilots were more likely to be female and have a younger mean age than people with PD in the community (see Table 20). At four of the pilot services the proportion of people referred who were from BME communities was similar to the proportion in the general population. In the remainder it was lower, for instance in two services where BME residents make up one in six of the population, less than 3% of those referred to the service were from BME communities. While most pilot services set out to encourage referrals from a range of different sources, over 90% came from community mental health services, and most of those who came from other sources had had previous contact with them.

There was marked variation in the proportion of people referred to each of the pilots who were eventually taken on for direct services. Two pilots provided access to services following an initial meeting where service users completed a basic assessment, and in one a simple crisis plan. As a result they took on between 90% and 100% of all those referred. In contrast, the remaining pilots took on, on average, half of those referred. However it should be noted that, for most pilots, people were sometimes referred for assessment with the aim of helping existing service work more effectively rather than with the expectation they would be taken on by them. Nonetheless, variations in the proportion of people taken on are interesting as are differences in the characteristics of those who were, and were not, taken on for direct service provision. Men were less likely to be taken on by services than women, an association that was largely the result of people with a past history of violence towards others being less likely to be taken on by services.

Table 20. Comparison of characteristics of people referred to and taken on by pilots, with those from previous studies of people with personality disorder (and *borderline PD only).

Learning the lessons 2007	Learning the lessons 2007	Moran *et al.* 2000	Davies & Campling 2003	Chiesa & Fonagy 2000	Hubband *et al.* 2007	*Bateman *et al.* 1999*	*Davidson *et al.* 2006*
Cross-sectional study	Cross-sectional study	Cross-sectional study	Cohort study	Cohort study	RCT	*RCT*	*RCT*
Treatment Population All PD	Treatment population All PD	Primary care attenders	Inpatient treatment	Inpatient treatment	Treatment population	*Treatment population*	*Treatment population*
						Borderline personality disorder	*Borderline personality disorder*
Referrals	**Taken on by services**	All PD	Mixed PD	Mixed PD	Mixed PD	*Borderline personality disorder*	*Borderline personality disorder*
1087	621	303	52	46	87	*42*	*106*
35.7 (9.9)	36.1 (9.9)	41.9 (14.6)	27.2	31.6 (7.9)	36.2 (9.6)	*30.3*	*31.9 (9.1)*
34.2	27.4	32.7	42.0	32.0	48.0	*32.0*	*16.0*
6.5	6.6	20.5	–	–	–	–	*0*
94.1	94.5	–	–	100.0	–	–	*100.0*

Detailed clinical data were obtained from only a minority of service users, so these need to be interpreted with caution. These data show that across all 11 pilot services, levels of personality disturbance and impairment in social functioning were high. 95% of people had a SAP-AS score indicating the likelihood that they had a personality disorder. A mean score of 14.1 on the SFQ is similar to that reported in studies of people with PD who engage with services (Huband *et al.* 2007) and is equivalent to levels of disturbance seen in acute mental health settings (Tyrer *et al*. 2005b). Data on suicidal behaviour collected by five of the pilots showed that almost half had attempted to end their life during the previous 12 months, in contrast to population-based studies which suggest a life-time rate of 3% (Crawford *et al*. 2005).

Approximately half those taken on by services had left by the end of the follow-up period, with 14.0% having completed an episode of care and 25.1% having dropped out of contact with services or having left the service early for other reasons. Previous observational studies have reported similar levels of drop-out among people with PD, with baseline levels of hostility and impulsivity predicting those most likely to leave early (Gunderson *et al*. 1989; Huband *et al*. 2007). The associations that we found, between retention in the service and self-referral and between leaving early and ethnicity, require further investigation.

7.1.3 Delphi study

After three rounds of the Delphi exercise, consensus was reached on 21 (39%) items. The level of consensus we found was lower than that reported in most other Delphi studies (Fiander & Burns, 1998; Murphy et al. 1998). This was despite the fact that the benchmark we set for consensus was lower than that used in most other Delphi studies (Cheadle *et al*. 2000; Weigl *et al* 2004). The lower level of consensus we found may be because of the broader range of participants that we included, e.g. service users, or it may reflect the early phase in our understanding of the development of dedicated services for people with PD and the relative absence of evidence in this field. Higher levels of agreement among expert authors than among the other two stakeholder groups provides tentative support for the former hypothesis.

Participants reached consensus in favour of 20 items and against one: the proposition that 'Most people with PD do NOT require dedicated services'. This proposition is particularly significant because of the implications it has for current service provision. At present most areas of the country have no dedicated service for people with PD and this situation could not be changed without considerable new investment in services, or reconfiguration of existing services. Most of the other findings from the Delphi study support the views of service users and providers obtained in the qualitative components of the study and are discussed further in Sections 7.3 to 7.6 of this report.

Views on outcomes which should be used to judge the performance of dedicated services showed small but important differences between stakeholder groups. Differences in views of service providers and service users have been seen in other settings (Perkins, 2001; Wensing & Elwyn, 2003). The greater emphasis that service users placed on symptoms of mental distress is noteworthy because previous treatment studies have suggested that improvements in mental health are less likely to occur than other outcomes, such as reductions in self-harming behaviour (Binks *et al*. 2006).

Preferences for service development showed a higher degree of consistency, with a preference for outpatient psychological services, and little support for inpatient treatments for those with severe PD. The low ranking of therapeutic communities is perhaps surprising, given the emphasis on day-TC models among the pilots: it is possible that this item was interpreted as referring to inpatient TCs rather than the outpatient models being evaluated in this study. The item to receive the highest ranking was one which was suggested by service users: 'A service which aims to reduce stigma and discrimination experienced by people with PD'. While this would appear to be the aim of much of the support that dedicated services offer to those working across a range of health, social care, voluntary sector and forensic services the optimal organisational structure through which services may achieve this aim remains unclear.

7.2 Study strengths and limitations

The wide variety of different treatment approaches adopted by the different pilots meant that we were able to examine a range of different ways of working with people with PD. A large amount of qualitative data was collected and analysed. The study involved interviews with 89 service providers and over 100 service users. We believe that the approach we took to obtaining data from service users is the first time that a user-led research project has incorporated national recommendations for this type of study (SURGE, 2007). The service user research team were involved at every stage of the study: from sampling and data collection through to analysis and writing of the case studies. This high degree of involvement meant that the perspectives of service user researchers were fully incorporated into every stage of the research process.

Having collected data from a range of different perspectives we have been able to capture key learning from the development of these services. Analysis of data from the organisational evaluation and user-led qualitative study was conducted by two separate teams. While the two teams worked closely during the planning stages of the project, in preparing this report there was no consultation during the process of data analysis. Comparison of findings from these two aspects of the study allowed a degree of triangulation to occur and the emergence of several key themes across these two aspects of the project increases the internal validity of the study findings.

In an effort to facilitate synthesis of data we planned a consensus-building exercise to examine the level of consensus there was on important aspects of the organisation and delivery of services and the broad range of stakeholders we included, together with the high response rate we obtained, means that we can have confidence in the findings of this exercise.

However, the study had a number of limitations we would like to discuss before considering implications of the study findings.

7.2.1 Timing of the study

The timing of this study coincided with the first two years of the operation of most of the pilot services. While this meant we were able to track some of the challenges services faced, and report on the steps they subsequently took to manage these, it is important to note that services were in transition and some of the problems we identified may have been resolved in the period after data collection stopped. Most of the pilots were based on innovative models for working with people with PD and were reviewing and adapting the services they provide during the course of the study. Correspondence with staff and service users in the pilots suggests that this process has continued since data collection ceased and it is important to note that these data therefore may not describe services as they are currently being delivered. This is equally true of the qualitative data collected from the first wave of service users and quantitative data on service provision, which also represent a snapshot of service activity levels at an early stage of the development of these services. Conversely, issues related to how services manage new referrals once tier three interventions have reached capacity were only just beginning to emerge.

7.2.2 Response bias

During the period when study data were being collected, plans for future funding of the pilot services had not been agreed. Those working in the pilot services may have viewed this study as part of a process of evaluation that would influence future funding decisions. In this context it is likely that service providers and, to a lesser extent, service users, may have felt they needed to present their service in the best possible light. This limitation needs to be taken into account when interpreting study findings.

7.2.3 Study samples

Initially we relied on managers and clinical leads at pilot services to identify service users and referrers who might be willing to participate in the study. Some of service users who took part were identified opportunistically when conducting interviews with other users.

Referrers were asked to suggest the names of colleagues who might be willing to be interviewed; however most of those who took part were nominated by service leads. We do not know how representative service users and referrers were of all those who had used services provided by pilots, or tried to refer people to them. Some of the service users and referrers that we interviewed were critical of aspects of the pilots but it is possible that teams directed us to users and referrers who had a good experience of the pilot service. In consultation with service providers we decided that service users who were still in the process of being assessed or had had difficult leavings should not be asked to participate in the study. We would have liked to have obtained a complete list of users and referrers to these services and attempted to interview a purposive sample of each. However, we did not have sufficient resources, or ethical clearance, to do this and our reliance on pilots to direct us towards those willing to be interviewed may have affected the data we subsequently collected.

7.2.4 Cohort data

Our failure to develop a method for obtaining informed consent from service users that was acceptable to staff in the 11 pilot services means we were unable to collect longitudinal data on clinical and other outcomes. The absence of follow-up data on service utilisation is particularly disappointing given feedback from commissioners about how important this information is to decisions about long-term funding for these services. In retrospect, our original plans to collect detailed longitudinal data on mental health, social functioning, service utilisation and other outcomes were overly ambitious. The geographical spread of the services meant it was impractical for the small research team employed on the project to collect baseline data from the study sample. Front-line staff in the 11 pilots usually had no previous experience of obtaining informed consent from their service users and were concerned about the impact that asking people to take part in a study would have on their efforts to engage people in their service. The situation was further complicated by detailed plans that some of the pilots had for conducting local evaluations, some of which were already in place at the point at which this project was commissioned. However, we were able to reach agreement with most of the pilot services about measuring key clinical variables as part of their assessment process. We were then able to obtain Ethics Committee approval to access anonymised copies of these data.

Differences in the stage of development of pilot services and differences in the approach that pilots took to data collection meant that the quality and quantity of data we collected varied. We were not in a position to insist that pilots collect these data and some pilots chose to modify the instruments that we hoped they would use: this further limited data quality.

Nonetheless, we were able to obtain basic demographic data and information on service provision from all 11 pilot services and collect additional baseline data on personality traits, social functioning and service utilisation from most of the services. These data have allowed us to compare the 11 pilot services and explore differences in characteristics of people who made contact and used these services.

Minimum dataset data were collected from a minority of all those referred to services and while we collected data from over half those taken on by services, missing data mean that differences in SAP-AS scores, social functioning and service utilisation need to be interpreted with caution.

7.2.5 Delphi study

The primary aim of the Delphi study was to examine the level of consensus around key aspects of the organisation and delivery of dedicated services for people with PD. Our response rate was generally higher than that obtained in such studies. We included a broader range of stakeholders and provided more feedback to participants on the responses that others had given in previous rounds (Murphy *et al.* 1998).

While we included a sample of 30 service users, we were unable to identify a sample of carers who could participate in the exercise. We considered whether to include a sample of commissioners of mental health services in the exercise but interviews with commissioners suggested that while they had clear views about the place of dedicated services for people with PD within other health and social care services, most had insufficient knowledge of services to feel able to comment on specific aspects of service delivery. While the three stakeholder groups we used were well placed to comment on the organisation and delivery of services, they all shared a commitment to services for people with PD, and may not be best placed to judge whether dedicated services should be more widely delivered.

7.3 Areas of convergence

In several key areas, views of service users were congruent with those of providers and these, in turn, where supported by findings of the Delphi study. These were principally around the organisation and delivery of direct services, the personal attributes of staff working in dedicated services, the way that front-line staff should be supported and managed, and the most effective methods for delivering indirect service provision.

7.3.1 Organisation and delivery of direct services

Interviews with service providers identified key features of the organisation and delivery of dedicated services for people with PD that were widely supported across most of the pilot services. Several of these features were echoed by responses of service users and carers whom we interviewed and others were endorsed in the Delphi exercise. These key features are listed in Text Box 1

Text Box 1: Important features of dedicated services for people with PD

They should be delivered over a relatively long period of time, e.g. years not months.

The service must be consistent and reliable.

Comprehensive communication within staff teams is vital; services should have a clear information-sharing policy, communicated to the client during induction.

Teams should be made up of people with a range of professional and non-professional backgrounds.

Users and their carers should be involved in making decisions about service development.

Responsibility for client welfare should be shared by members of a team and / or the community, rather than by individual members of staff.

Limits on the availability of staff and other boundaries need to be made clear to service users at the start of treatment and stuck to throughout treatment.

Services need to demonstrate that the user is valued and valuable. The approach should be validating, rather than dismissive, of the person's experience and aim to increase self-acceptance.

Short and long-term goals should be set, negotiated with clients, at an early stage.

Services should provide and promote choice, self-efficacy and personal responsibility and avoid trying to control or coerce service users.

Services need to be able to deliver social as well as psychological interventions.

Services should be able to arrange more intensive services at times of crisis, including home treatment and / or residential care.

Services should try to obtain users' consent to contact, support and inform carers.

Systems should be in place for ensuring users are prepared for leaving and that the process through which they will leave is made clear and discussed well in advance.

Services need to offer cultural sensitivity, mindful of the experiences of discrimination on the basis of race and ethnicity.

7.3.2. Personal attributes of staff working in dedicated PD services

One of the items in the Delphi study that attracted the highest level of consensus was that 'the personal qualities of staff – such as self-awareness and ability to observe boundaries – are more relevant to working well with PD clients than professional qualifications'. Interviews with service users and providers generated a more detailed description of personal qualities that staff working in dedicated PD services should have. These are listed in Text Box 2. While these qualities include many features that would be desirable in anyone working in any health or social care context, they place particular emphasis on a person's capacity to reflect on their work with service users and an ability to hold back from trying to make decisions for people or to control their behaviour.

Text Box 2: Desirable characteristics of staff working with people with PD

The ability to be responsive and work flexibly with service users, but not at the expense of neglecting appropriate boundaries.

The ability to empower service users, even if this means letting them make some mistakes. Staff who are controlling may be unsuited to working with people with PD.

Staff need to be emotionally mature and have a high degree of personal resilience.

While retaining a positive attitude, staff need to be able to accept the limitations of what can be done.

Staff need to have a capacity and a willingness to reflect on themselves and their work.

Staff need to be able to discuss their own mistakes or uncertainty.

Staff need to be able to be able to balance their work life with other aspects of their life.

They need to be willing to work as members of a team, to reach compromises and accept the process of shared decision making and / or the decision of the clinical lead when agreement is not possible.

Staff need to be informed and knowledgeable about personality disorder: its aetiology, its impact and the psychological processes through which problems occur.

Staff need to be empathic, non-judgemental, open, genuine, 'real', and accessible.

7.3.3 Managing and supporting front-line workers

A consistent theme of interviews with service providers was that staff working in dedicated services needed to be supported by clear management structures and have ring-fenced time to meet together and reflect on their practice. Service leads described how staff working in PD services needed support from strong leaders who were able to contain the anxieties that were often induced by working with this client group. Commissioners of services recognise the importance of dedicated, strong leaders but warned that the leadership skills of others need to be developed in order to ensure that services could become self-sustaining.

The view that staff working in dedicated PD services need to have an opportunity to come together to reflect on their practice, their relationships with clients and the impact their work has on team members, was one of the items that reached the highest levels of consensus in the first round of the Delphi study. Staff in several pilots stated that these fora should ideally be facilitated by a person who is independent from the team because this enabled people to examine their feelings without the restraint which might apply if a manager were present in a supervisory role. Pilots services that comprised more than one team, those employing large numbers of part-time staff and those that have to provide services over dispersed sites reported difficulties in organising team supervision. Where team supervision is not possible, regular individual supervision takes on additional significance.

7.3.4 Delivering indirect services

Service providers gave a detailed description of their work in training and supporting people working with people with PD in other settings. Service providers delivered this training and support to people across a wide range of different settings, though much of the focus was on working with staff in mental health and social care. Key themes to emerge from these interviews were that training worked best when it was delivered to teams rather than to individual members of staff, and when it focused on specific examples of working with people with PD as well as general principles. Service leads told us that support and advice from those working in dedicated PD services was valued more highly when it was delivered by people who were involved in direct service provision. Student placements and secondments from other services were also seen as important methods for increasing understanding of PD and its management. Several services offer case consultation, which is seen as providing staff with time to reflect on their work – a resource which is often limited, especially among staff working on inpatient units and in CMHTs. People working in these services welcomed the support and training they received from pilot services. Some told us that it was difficult to find time to schedule meetings around case consultations and that their preference was for general training sessions. Service providers told us that case consultations had helped to improve the quality of care of people with PD, and resulted in better use of available resources and cost savings. This view was supported by several of the commissioners whom we interviewed.

7.3.5 Involving service users

Staff at pilot services told us that user involvement is an important part of their plans for improving the quality of the services they provide. However, the extent of service user involvement and the methods used varied considerably between the pilots. Service commissioners identified user involvement as a weakness in some of the pilot services. While all involve users in making treatment choices and decisions about the services they receive, several have been unable to set up and sustain ongoing methods for involving users in planning the development of services. In some pilots, such as The Haven, users have been central to the development of services. In others, particularly those that had little or no PD service prior to the pilot, there was no culture of involving people with PD in local service developments. As pilot services mature and numbers of people with PD who have used dedicated services increase, user involvement should become easier. Given the early stage of development of dedicated PD services, active user involvement is important in shaping future changes to services.

7.4 Areas of divergence

7.4.1 The assessment process

Accounts of service users and providers were notable for the high levels of agreement on many of the key elements of service delivery. A significant exception to this was around the issue of assessment. The length, depth, and purpose of the assessment process varied greatly between different pilot sites, ranging from a basic requirement to describe current problems and agree a crisis plan, to more detailed assessments conducted by the case-management service and those delivering day-treatment programmes. Staff at pilots where detailed assessments were used emphasised the importance of getting a complete picture of a service user's problems, their personality and their personal history. While a minority of service users told us they appreciated the detailed assessment they received because it gave them confidence in the service, most were concerned about the level of support they had been offered while being assessed. Some service providers told us it was important to limit the amount of support a person received prior to a decision to take them on, in order to try to limit the disappointment service users would experience if it was decided they could not use the service. Several service users spoke of the distress they experienced during the assessment period as a result of conversations exploring painful past experiences and uncertainty about whether they would be taken on by the service. We believe these data support the view of Delphi panellists that it is important those referring people to dedicated PD services continue to provide regular support during the assessment period. Findings from interviews with service users suggest that the length of assessments dedicated services provide should be reviewed and, where possible, reduced.

7.4.2 Use of the label 'personality disorder'

Given the commitment that pilot services make to being open and honest with service users it is interesting that not all are explicit about the use of the term 'personality disorder'. While some are clear they provide services to people with PD, others use terms such as 'interpersonal problems' and 'complex cases' to describe the focus of their work. Views of Delphi panellists also varied, with 61% rating their response to the statement: 'Information about services for people with PD should always use the term personality disorder' as neutral.

The use of the term 'personality disorder' also gave rise to a wide range of different reactions among the service users we interviewed. Whilst some people felt angry and resentful about being labelled with a personality disorder, others identified with the label and felt it helped them understand the nature of their difficulties and gave them a better idea about how they could try to overcome them. Previous research has reported that service users feel that the treatment they are offered becomes worse when they are given this label (Ramon *et al*. 2001), and service users in this study were concerned about the impact the term might have when they no longer had contact with this dedicated service. Clearly it is important that where this label is used, services take time to explain its meaning and explore the response that service users have to its use.

7.4.3 Care Programme Approach responsibilities

Consensus was reached in round three of the Delphi study that 'Services for people with PD should provide care coordination under the care programme approach'. Most, but not all, the pilot services took on CPA responsibilities and services that did this felt it provided a helpful means of coordinating the care people received. Service providers told us that people with PD were sometimes in contact with multiple agencies prior to their referral, and that the Care Programme Approach provided a structure to review this and ensure clear communication between all those involved. Some pilots were concerned that CPA procedures were primarily designed for people with mental illness and were not suited to the approach they were using which emphasised the importance of service users becoming more self-reliant. A novel approach to this problem was being pursued in some of the day-TCs, where service users become coordinators of their own care. Other services which took on CPA responsibility did so with the explicit aim of working with service users to discharge them from care under CPA at a later date. There was widespread agreement that it is impractical and inappropriate to take on CPA responsibilities when delivering short-term or Tier one services to service users. Disruption to continuity of care that would result from care being transferred when people are being taken on for a limited number of sessions of skills training or psychological therapy may also make this impractical. However the data we collected suggests that the benefits of transferring care under CPA when people are taken on by Tier three services outweigh the potential harms.

7.4.4 Provision of 24-hour crisis support

While there was general consensus that people using dedicated PD services need to have access to 24-hour support at times of crisis, service providers did not agree about whether this needed to be provided by the PD service itself. Among Delphi study participants 40% were neutral when asked whether out-of-hours crisis support should be provided 'in house', a clear majority (67%) of service providers stated that they should not. In contrast, 71% of service users who took part in the Delphi exercise stated that dedicated services should provide their own crisis support service. This echoed finds from the user-led qualitative study where users of pilot services that provided an in-house crisis service told us that they were greatly valued and service users at pilots where this was not provided told us they wished it were.

Several services provided some kind of support outside normal working hours: for instance the service that works with people with PD and substance-misuse problems gives service users access to staff by telephone up to 8.00pm every evening, in keeping with the DBT model. Other services have organised formal systems through which service users can access peer support outside normal working hours. One of the pilot services provides access to face-to-face support 24 hours a day. Users of this service told us how much they valued this. Other service providers told us that organising special access to care at times of crisis ran counter to their efforts to help people become more self-reliant. They argued that people with PD needed to be helped to develop ways of coping with crises that did not rely on eliciting an immediate response from service providers. An intermediate model was the offer of a guaranteed emergency appointment at set hours every weekday morning, and the use of email communication, with response on the next working day. It seemed that people in crisis can sometimes wait for support if they have certainty it will be delivered at the expected hour – and this was true also of the use of crisis beds in one service, where use is predominantly booked in advance on a respite model.

Service users told us about their dissatisfaction with sources of urgent help such as EDs. Many of the pilot services provide training and support to colleagues working in EDs aimed at helping them understand the nature of crises that people with PD experience and how to intervene at such times. Previous research demonstrating that staff who work in emergency medical services may respond to people who self-harm with frustration and even hostility (Jeffery, 1979) provides support for these initiatives. However, time pressures and the need to prioritise those who require urgent medical treatment mean that EDs are not an ideal environment in which to try to manage the emotional crises of people with PD. Provision of in-house crisis arrangements was recommended as part of the development of dedicated PD services (National Institute for Mental Health, 2003b) but comes at a cost, and the cost–benefits of providing separate services have not been evaluated. Dedicated services for people with PD must attend to people's need for more intensive support at times of crisis; peer support networks may provide a cost-effective way of providing this.

7.4.5 Self-referral

All but two of the pilot services received most of their referrals from providers of health and social care. The exceptions to this were the service user network, which would only accept self-referrals, and the youth advisory service. Several other pilot services were prepared to accept self-referrals, but only four of these – including the voluntary sector-based skills development service, and the information and counselling for adolescents with personality disturbance – took appreciable numbers of people who self-referred. Other services explicitly stated that they could not take people who self-referred. Reasons for this included a concern that the service user was not in receipt of support during the assessment process, and that allowing access to self-referral might mean that the services would end up taking people whose level of need was not high enough to be prioritised by a specialist team.

Those services that were open to self-referral told us that they were keen to be able to work with people who might have been excluded from services, and that allowing self-referral would promote personal agency and self-reliance. While the Delphi study generated consensus that people with PD should be able to self-refer to dedicated PD services, it is noteworthy that only 54% of service providers supported this view.

The quantitative data we collected revealed that people who self-referred were just as likely to have had previous contact with mental health services. Mean SAP-AS and Social Functioning Questionnaire scores did not differ between the two groups. A non-statistically significant reduction in rate of drop-out from services among those who self-referred provides tentative support for the notion that encouraging self-referral may be one method for increasing retention in services.

Previous research conducted in mental health and substance misuse settings has generated conflicting findings on the relationship between self-referral and engagement with services, with studies reporting both higher and lower levels among those who self-refer (Raynes & Warren, 1971; Allan 1987; Bell *et al*. 1997). Previous work using focus groups to obtain the views of service users reports that the people would like the option of referring themselves to services (Haigh, 2002). Given the emphasis that pilot services place on promoting choice and autonomy, these data provide limited evidence to support the view that dedicated services for people with PD should be open to self-referral.

7.4.6 The role of medication

Service providers varied in whether or not they believed that medication was of value in the treatment of people with PD. Service providers generally told us that people referred to them were taking too much medication and that they had an important part to play in helping to reduce this. Some commissioners saw reductions in use of medication as a way of generating cost savings to support future funding of dedicated PD services. Some of the pilots that provided day-TCs stated that coming off medication was a requirement for entering tier three services: for instance, it was stated that high use of benzodiazepines could blunt psychological awareness and insight. Interviews with service users at these sites revealed that many had found this difficult and some had decided against using them because of this requirement.

While most services took an interest in medication that people were being prescribed, opportunities for changing this were limited in some by the absence of medical input. Two-thirds of Delphi participants supported the statement that 'Teams delivering services for people with PD should have regular input from a psychiatrist'. Some service leads told us that their budgets were insufficient to pay for what is a relatively expensive resource, but others felt that the presence of a psychiatrist could promote a medical model of PD that they were keen to counter.

When asked whether 'Dedicated services for people with PD should help service users reduce, with a view to stopping, psychiatric medication' most stated that they were neutral. Service users were less likely to state that they were neutral than providers and expert authors, with 16% disagreeing with this statement and 48% supporting it. While research evidence suggests that long-term use of psychotropic medication is unlikely to benefit people with PD (Roy & Tyrer, 2001), people with PD are at higher risk of developing depression and other mental disorders for which psychotropic medication can be of value. While most services report that helping people to stop taking psychotropic medication can facilitate the development of better ways of coping with emotional distress insistence that medication be stopped may deter some potential users from engaging with services.

7.5 Innovation

While health and social care services in general and psychotherapy services in particular have always assessed and treated people with PD, few services in Britain have focused specifically on the needs of people with PD. Those that have, have generally provided residential services - very few have delivered community-based services. As a result, all 11 pilot services have had to innovate. The case studies in Appendix 1 provide a detailed description of these services. In this section we highlight notable examples of innovation that link some of the pilot services.

7.5.1 Day therapeutic communities

Therapeutic communities are one of the best-established models for working with people with PD. With their emphasis on group learning and peer support, they aim to promote insight and self-efficacy. While therapeutic communities have always assessed people in the community, historically their emphasis has been on residential treatment. Observational studies comparing the outcome of people with PD who are treated in residential therapeutic communities suggest they are less likely to self-harm and have lower levels of subsequent service utilisation than those who are not so treated (Chiesa & Fonagy, 2003; Davies & Campling, 2003). Five of the 11 pilot services stated that the development of their service was based on, or influenced by, therapeutic community principles: four involved setting up day treatment programmes and the fifth, a series of outpatient groups for people with PD.

Like residential TCs, the day-TCs use a variety of techniques to empower service users and promote insight. Service users, or 'members', are involved in decisions about content of groups and whether someone new can join the programme. They also share the responsibility for ensuring that agreed boundaries are adhered to. Established members are elected to more senior positions and given additional responsibilities for overseeing the service. Opportunities for involving members in practical decisions about living arrangements are inevitably more limited than those in residential TCs, and members can not be included in discussions following crises as quickly as when members live together 24 hours a day.

Concerns have previously been raised about the high level of commitment required of service users if they are to leave their home and live in a residential TC. This may be one of the reasons why residential TCs work with a minority of the people that are referred to their service. Day-TCs ask less of their members and our data suggest the proportion of people referred to these day-TCs who engage with services is higher than for those providing residential treatment (Rutter & Tyrer, 2003).

Previous research has indicated TC services that combine residential and outpatient treatment are at least as effective as those based solely on the former (Chiesa *et al*. 2004). However, given that the intervention is one which is based on peer interaction and support, there presumably comes a point where it effectively ceases to be a 'community'. Therapeutic communities are cultures which take time to develop and mature, and this was especially difficult within the life of the pilot funding. Service commissioners questioned the intensity of the service provided by some of the day-TCs and other pilot services. Treatment programmes at pilots using a day-TC model varied from five days to one day per week. The intensity of the service has important implications for the capacity of the service and its cost-effectiveness. The impact of different models has not been examined. It is also unclear whether the advantages of a day-TC in terms of reduced cost and increased level of engagement are offset by a reduction in impact on treatment outcomes as compared with their residential counterparts.

7.5.2 Encouraging peer support

Service providers across the pilot sites described the value of peer support and most provided some form of intervention that brought service users together in groups. Several services had developed ways of harnessing peer support as a method of helping people cope with crises outside normal working hours. The internet-based 'P2P' (peer-to-peer) service developed in North Cumbria provides a notable example of this which may have particular application in areas that are sparsely populated (see Appendix 1). Such services offer the potential for service users to develop ways of coping with crises that do not rely on contact with health- and social-care professionals. The role that service users play in supporting each other may also help to improve self-efficacy and self-esteem.

However, some service users reported that they had encountered problems with systems designed to facilitate peer support, stating that they felt they ended up taking on other people's problems. Others talked of cliques developing which led to new sources of tension and distress. Systems for facilitating peer support are still at an early stage of development and methods for guarding against abuses of such services may need to be further refined.

7.5.3 Other examples of innovation

Many people with PD describe a childhood characterised by inconsistent or absent care (Widom, 1989; Luntz & Widom, 1994). People with PD often present with concerns that they have been denied help and support later in their lives, which are often based on actual experiences of being excluded from mainstream services. Several pilot services have responded to this sense of unmet need by providing access to help and support that people may have been denied in the past. For instance, at The Haven in Essex service users have access to short-term residential support. In other services, such as the Complex Cases service in Cambridge, service users are given the right to book themselves in to an open-access clinic with a senior member of the team. Users of these services told us that they valued them, and service providers told us that, contrary to expectations, they are rarely over-used.

Innovative approaches used by other pilots involved extending access to a service that was already available to people with other mental health-related problems. The ways that services, such as support for primary care workers, case management and early intervention for adolescents, were modified to suit the needs of people with PD are described in detail in Appendix 1.

7.6 Challenges

Most of the data we collected suggest pilots were delivering services that were valued by users, referrers and commissioners. However, several concerns were raised, some of which have been discussed in Section 7.4. Others include the effectiveness of services, the management of people with ASPD, working with people who show little motivation to change, working with carers, and procedures for discharging people from dedicated services and providing aftercare.

7.6.1 Service effectiveness

Some of the referrers we interviewed raised the issue of how effective dedicated services were in helping people with PD to change. The issue was also repeatedly raised by commissioners, who tended to focus on whether dedicated services resulted in reductions in expenditure on other services. Several service providers have collected local data that charts reductions in use of emergency medical and other services among people taken on by their service. However, some referrers commented that there were many other people with PD in the local area who were not motivated to make use of the service and for whom the development of the local service had therefore made no difference. These comments raise the issue of whether, and if so, how, dedicated services should try to engage people who have PD and who have little motivation to change (see below). They also highlight how weak the evidence base is for the effectiveness and cost-effectiveness of community services for people with PD. With the exception of the DBT model being used by one of the pilots, and the Social Problem Solving groups run by another, none of the interventions being delivered by pilot is based on evidence from high-quality research studies. It is therefore unsurprising that Delphi respondents did not oppose the statement 'Evidence from research studies about "what works" for people with PD is too limited to guide service delivery' (60% responded that they were neutral, 22.5% supported the statement and only 17.5% opposed it).

Data we collected from users of pilot services suggests that many people value the service provided by the pilots, and their accounts provide personal testimonies in support of the value of these services. However, it is equally clear that self-harming behaviour among people with PD tends to reduce over time and that many people with PD make changes to their lives without input from dedicated services (Zanarini *et al.* 2003).

In the short-term the support of colleagues in other services and the personal accounts of users should be sufficient to ensure that such services continue to be funded. All pilot services have collected some audit data tracking changes in service utilisation among people prior to, and following, referral to their service. We believe they should need to continue to audit the impact of their work on levels of use of other services and that further research is required in order to compare different approaches to helping people with PD if such services are to be sustained and extended in the future.

7.6.2 Motivation to change

Many, perhaps most, of the users taken on by these pilot services were ambivalent about whether they wanted to receive a service. Many users told us that previous experiences of health and social care had left them suspicious of services and doubtful about whether or not they could be helped. Staff working in all pilots told us they expected many people referred to them would be unsure whether they wanted a service and agreed that a central part of their work involved efforts to build trust and promote engagement.

Pilot services provided a range of interventions to individuals and groups aimed at providing information about PD. Some groups were explicitly set up to explore and promote motivation to change. Service providers told us that a degree of motivation to change was essential if people were to use individual or group psychotherapy. Data from the cohort study shows that 91% of people on whom we obtained clinical data believed there was 'something they wanted to change about their personality'. While the degree of motivation to change among people with PD in community settings is unknown, one study reported that only 25% of those with dual diagnosis of mental disorder and PD who were receiving services from an assertive outreach team wanted to do so (Tyrer *et al*. 2003a). The high degree of willingness to change among people in contact with these services suggests that many of those with PD who were not willing to change were not referred to, or taken on by, these services: this view was supported by referrers who told us they worked with people with PD who had declined referral to these services.

One exception to this was the Leeds Personality Disorder Network, which specifically targeted people on the basis that existing services had not found it possible to work successfully with people, rather than on the basis of their interest in using a dedicated PD service. A quarter of those on whom we received quantitative data from this team stated they did not want to change aspects of their personality. Local referrers whom we spoke to valued the willingness of this team to work with what were seen as being those difficult users. Perhaps not surprisingly, this team reported difficulties in trying to engage service users in psychological treatments and this illustrates a dilemma in planning services for people with PD – how should services respond to those with high levels of need and low levels of motivation to change? Most members of our Delphi panel did not support the use of home visits or assertive outreach for people in contact with PD services. While pilot services encouraged people to attend, few undertook outreach and they tended instead to emphasise the importance of peer support and helping people with social and other practical problems as a way of promoting engagement with services.

Methods for working with people with PD who do not want to change their personality are being developed. One such approach, nidotherapy, focuses on efforts to change the person's environment rather than their personality (Tyrer, 2002; Tyrer *et al.* 2003b). Such methods could play a role in helping dedicated PD services in their efforts to engage and work with people who have severe PD but show no interest in understanding and modifying their emotions and behaviour.

7.6.3 The needs of ethnic minority service users

The proportion of people from BME communities who were referred to pilot services was generally lower than estimates of the proportion of BME residents in the local people. Reasons for this are unclear. It has been suggested that PD is less prevalent among BME communities in Britain (Strakowski *et al*. 1995), but there is little evidence to support this notion. The prevalence of PD among people from BME communities was slightly lower in the Household Survey of Psychiatric Morbidity, but the difference was not statistically significant and was based on only 18 people from BME communities who were thought to have PD (Coid *et al*. 2006). An alternative explanation for the low rate of referral is that people with PD from BME communities were less likely to be referred to dedicated PD services. Previous studies have reported lower levels of referral and uptake of psychological services among people BME service users (Littlewood & Lipsedge, 1989), and reports from service leads highlighted the problem of assessing the minority of BME users who find it difficult to communicate in English.

We also found evidence that BME service users who engaged with PD services were less likely to leave them prior to completing a package of care. Again, reasons for this are unclear. This finding was not based on an apriori hypothesis and while it was statistically significant it is possible that it was merely a chance finding. There was also missing data, one service did not have data on ethnicity on a quarter of referrals. Interviews with service users raised issues about how minority groups are treated especially in group settings.

Delivering race equality in mental health care is a national service priority (Department of Health, 2003) and we believe our data highlighted the importance of dedicated PD services accurately record ethnicity and ensuring that the interventions they deliver are culturally sensitive.

7.6.4 Working with people with ASPD

Most of the pilot services excluded people with ASPD and several explicitly excluded people with this diagnosis. While a substantial minority of people taken on by pilot services had a forensic history, between 3% and 9% of those who provided quantitative data had been charged with an offence during the previous six months, few if any appear to have had ASPD. Several pilot services provided tier one support to probation officers and other criminal justice workers and the case-management service employs part-time probation officers as part of its network.

Providers of dedicated services spoke of their concerns that people with ASPD may be unresponsive to psychological treatment and could disrupt the care of other service users. Some referrers we interviewed spoke of their frustration that people with ASPD could not be referred to their local service, though others shared the concern about the impact people with ASPD could have on the care of other people with PD. Commissioners pointed out that, as most of the costs associated with ASPD are borne by criminal justice services rather than mental health and social care, the criminal justice system may need to finance the development of such services.

While an evidence base for community-based interventions for people with ASPD does not exist, this is equally true of other forms of PD that pilot services are prepared to work with. Randomised trials of Cognitive Therapy and Mentalisation Based Therapy for people with ASPD are in progress. Should such interventions be demonstrated to be beneficial, further consideration will need to be given by dedicated services as to how they can engage and treat such people: if not, ASPD will remain a diagnosis of exclusion. These issues will also be explored in greater detail in a report on a parallel study on the organisation and delivery of forensic services for people with PD which is due to be published in spring 2008.

(see: http://www.sdo.lshtm.ac.uk/files/project/84-sci-summary.pdf)

7.6.5 Carers

While several pilot services planned to work with carers as part of their original application for funding, we identified few where this had occurred. All services recognised the important role family and friends may play in supporting people with PD and service users were generally asked if they wanted carers to be included in review meetings. However, specific services for carers were rarely provided and several pilots told us that providing direct services to people with PD and indirect services to colleagues had been a greater priority.

A group set up by the Thames Valley Initiative was a notable exception to this. The group combined psychoeducation with efforts to promote peer support. Interestingly, members decided they should call themselves a 'family and friends group' rather than a carers' group. Much of the discussion in the group was about the way members tried to support someone important to them who had PD and it was felt the term 'carer' provided too narrow a definition of this role. Members talked about having to balance the service user wanting to be cared for with their hope of helping the person to become more self-reliant.

Service users told us of the central role that family and friends sometimes played in helping them make progress. Pilot services have been slow to work with significant others, but the work that has been conducted suggests this can be an important intervention that helps to support some people with PD.

7.6.6 Compulsory treatment

The issue of compulsory treatment of people with PD was notable by its absence from interviews with service providers and commissioners. Proposals for the reform of the 1983 Mental Health Act make it clear the definition of mental disorder that will be used will be simplified in order to ensure it can be applied to people with psychopathy and other forms of personality disorder (Department of Health, 2006).

While consensus was not reached on whether 'There are circumstances when it is appropriate to use the Mental Health Act to compel a person to attend community-based services for treatment of personality disorder', more people opposed (56.3%) than supported this statement (11.3%); service providers were more likely to oppose it (74.1%) than were expert authors or service users. This finding is in keeping with results of surveys of mental healthcare professionals who have previously voiced their opposition to plans extend use of the Mental Health Act in England and Wales to include people with 'psychopathy' (Crawford *et al*. 2001).

While forthcoming reform of Mental Health Act legislation may lead to a change in the way that services assess and treat people who are considered to pose a danger to others, providers of community-based services for people with PD clearly see little role for its use in the services they provide.

7.6.7 Discharge

Service users told us of their anxiety about being asked to leave pilot services. Service providers told us they were concerned that people with PD may have had previous experiences of being rejected or abandoned by others and that the discharge process had to be handled with great sensitivity. Most services took people on for set time periods which were made clear from the start. For instance, users of the primary-care-based community links service know in advance they will be offered up to six sessions with a worker. For most other services a more flexible approach was taken to the date at which people might leave. The Haven and the Service User Network aimed to keep open a place for all those who made contact with the service. Similarly the Leeds PD Network undertook to deliver long-term support to people with PD. However, service providers were also mindful of their limited capacity and accepted that, without throughput, they would no longer be able to take on new referrals. Despite this, several services were still at an early stage of developing plans for when someone left the service. In some instances the plan being discussed with service users was that they would be discharged without specialist interventions but with continuing support from primary care. In this respect the approach used by the GP liaison service in north London may be important in helping dedicated services work out how best to support GPs in their longer-term work with people with PD. Other services were exploring the possibility of formal mechanisms through which service users might continue to access peer support.

7.7 Implications for providers of dedicated services

7.7.1 More than one intervention

The diverse range of problems that people with PD experience means dedicated services have to be able to deliver a range of interventions. Delivering more than one intervention means people can be offered choice, which may of itself be therapeutic for a group of people who have often been denied choices in their pasts. Limits on capacity to deliver direct services mean that dedicated PD teams need to be able to provide tier one support to colleagues working in other services. Dedicated services need to be able to provide access to peer support, group and individual therapies and practical assistance to help people manage their social problems. Dedicated services need to consider how to develop interventions for people with PD who have significant needs but are unwilling to engage with psychological interventions, including those who present risks to others (see Section 7.6.2).

7.7.2 Assessment and engagement

Many people with PD are told that general services are unable to help them, and may therefore see dedicated services as 'the end of the line'. The stakes involved at the time of the assessment are therefore very high, and the process of assessment is often a stressful one. It is important that assessment processes are no longer than required and that service users are given clear information about what support is available to them during this process. The way feedback from assessment is delivered also needs to be carefully considered: reasons why someone is considered unsuitable for a service need to be carefully explained and options for alternative sources of help provided. Those services that use the term PD need to explain its meaning, to be aware of the negative connotation this term has in the minds of many and to consider the impact that using this term may have on the ability of the user to access other services in the future.

7.7.3 Delivering direct services

We have listed important considerations for those delivering dedicated services to people with PD in Text Box 1. Chief among these are the qualities of front-line staff (see Text Box 2), and arrangements for providing staff support. Service users want to know about the therapeutic approach that the PD services use. Maintaining a mystique about therapeutic process can leave users feeling disempowered. Most services therefore made concerted efforts to talk to users about the treatment approach they used. The rationale and extent of boundaries that service users will be expected to adhere to need to be carefully explained, as do arrangements for out-of-hours support and any boundaries relating to contact with peers. Service users highlighted the contact they have with administrative staff; training and support for administrative staff are also important.

7.7.4 Endings

Providers of dedicated PD services need to prepare users for moving on from the service at an early stage. The service users we interviewed told us how hard they thought moving on would be and many were worried that ending contact with the dedicated service would mean they would be denied all access to mental health services. Some services have responded to these concerns by allowing long term use of their service. However this approach is likely to limit the number of new referrals some services accept in the coming years. Most services had therefore begun to develop 'step-down' programmes through which people who have received a period of regular treatment can continue to access a less intensive component of the service, such as an open peer support group or occasional review meetings. Such approaches may enable service users to retain and further develop coping strategies and other skills they developed in their initial period of using the service. Consideration should be given to providing some form of further contact with the service, opportunities to access peer support, or means by which users might access the service again in the future.

7.7.5 Tier one interventions

Limited capacity of dedicated services to deliver interventions to people with PD mean that indirect service provision will remain an important part of the work of such teams. Staff mobility in the public sector means this needs to be part of a rolling programme and not seen as a one-off event. Service users can help direct provision of tier one interventions to those services they have experienced the greatest problems with. Indirect service provision may be more effective when it is delivered by those who also provide direct services. It is thought to be more helpful when delivered to teams rather than individual members of staff. General teaching on the aetiology and management of PD as well as detailed discussions of individual service users are both valued by recipients of tier one interventions.

7.7.6 Audit and research

Providers of dedicated services will need to continue to provide evidence of the impact of their interventions. While efforts continue to explore the impact of interventions on mental health, social functioning and quality of life, commissioners of services may be more interested in changes in service utilisation among those in contact with the service. Commissioners highlighted reductions in use of out-of-area placements and in time spent on mental health units. Service providers will need to ensure that they are working with people who are high users of other services and that ongoing systems are in place for monitoring changes in service utilisation among the people they work with.

7.8 Implications for general services

Dedicated PD services need to provide information and support to potential referrers about their service, how to prepare users for referral, and how to manage people with PD who are not referred. For those who are referred the assessment process can be a stressful one and users need support during this period. Not all those referred to a dedicated team will be provided with a service, so a message that referral represents a final or last chance of their gaining support can make the assessment process more stressful and potentially harm the service user.

Those working in dedicated services have identified a range of process factors that they feel should guide the delivery of services to people with PD (see Text Box 1). These stress the importance of open communication, explicit boundaries, reliability and consistency and support for those who provide services. We believe these factors are also relevant to those working with people with PD in other contexts, including mental health and social services.

7.9 Implications for service users

7.9.1 What dedicated services can provide

Dedicated services vary in what they provide. This is because of the area they serve, differences in the availability of other types of mental health and social services, and the local expertise and training of those working with people with PD. Those providing dedicated services recognise that people with PD have a range of problems including emotional and social problems: the interventions they deliver aim to combine practical help with psychological approaches to help people understand themselves, their relationships with others and try to help people develop better ways of coping. There are limits to what any service can deliver and services should be made clear at an early stage.

7.9.2 The assessment process

The assessment process can be difficult and may stir up distressing feelings. Services should make sure users are clear about what sources of help are available during this time. Not everyone who is referred to a dedicated PD service will want to use it. Some people may not be suitable for the service. For instance people who use alcohol or drugs every day may need to take steps to reduce their use of these substances. While dedicated services are used to helping people who have angry feelings and may find it difficult to control their temper, they need to be able to provide a service which is safe for staff and other service users and are usually unable to work with someone who threatens or tries to harm others. The team needs to explain the results of their assessment to service users and discuss alternative sources of help and support that are available should these be required.

Most, but not all, dedicated services use the term 'personality disorder' because they believe it summarises a group of problems that some people experience and indicates an approach to providing services that is most likely to help. However, people who have been given this label sometimes feel the treatment they receive is harmed as a result. Dedicated need to explain the terms they use, provide you with alternative sources of information about PD and discuss the impact the use of this term may have on the services that people subsequently receive.

7.9.3 Using the service

Those delivering dedicated services understand that many people with PD have had previous experiences of contact with services that have been unhelpful and, in some instances, harmful. They understand these experiences often leave people unsure about whether they want to have contact with health and social care professionals. Most of the service users who took part in this study told us of the benefits they experienced as a result of using dedicated PD services (see Section 4.3.6). They hoped that these might encourage people who are unsure about using these services to try them out.

One of the aspects people told us had helped most was also one of which they had initially been most wary – contact with other service users. People told us how hard it was to trust others. Those who went on to use groups successfully told us they had originally thought they could not talk to others in groups. For many, group work and peer support were the things they had found most helpful about a service.

Most services set rules and boundaries that govern what service users can expect and what is expected of them. These boundaries aim to make the service reliable and safe and are considered important by people who deliver services and those who use them. Staff at dedicated services need to take time to explain their boundaries and to help service users understand their importance.

7.9.4 Getting involved

Dedicated community-based services for people with PD are in an early stage of development. Staff are keen to get feedback from people about their experience of services. Service users who get involved can make a difference to the way services develop in the future. Some dedicated services also provide opportunities for users to play a more active role in delivering services and supporting others. Information about what people are expected to provide if they take on these roles, and what they may gain, must be made available. It is also important for people taking on these roles to find out what support will continue to be available to them should they need it.

7.9.5 Ending contact with the service

For many people, ending contact with a dedicated service is a positive step in response to progress that has been made. However, endings can be difficult, especially for those who have had previous distressing experiences of other endings. Staff at dedicated services need to take time to encourage service users to talk and think about endings and make plans for endings well in advance of a leaving date. Services need to ask users to prepare for leaving and consider other sources of help that will be available when this time comes. Some services will continue to provide access to a part of the service and others allow people to re-contact the service at a later date in order to review the situation and think about the pros and cons of further contact with the service.

7.10 Implications for commissioners

7.10.1 Priorities for service development

While general mental health and social care services need to be able to assess and support people with PD they currently lack that capacity to deliver interventions aimed at treating people with these problems. Existing psychology and psychotherapy services are able to deliver treatments for people with PD but may struggle to provide sufficient support and containment to enable people with severe PD to successfully engage with treatment services. Dedicated PD services deliver psychological and social interventions for people with severe PD and have the ability to combine these with structures to foster peer support and group-work and provide tier one interventions aimed at supporting colleagues working in general health and social care settings. Those involved in delivering community-based services for people told us that 'one size does not fit all', users of services told us that they valued services that offered choice. While the data we collected do not allow us reach conclusions about the cost-effectiveness of different approaches to working with people with PD, our findings suggest a dedicated service for people with PD should offer a range of individual and group-based interventions that combine psychological and social approaches to helping people with their problems and optimise opportunities for people to obtain peer support. This recommendation is in keeping with findings of our Delphi study that also highlighted the value of case management and day-treatment programmes and highlighted the importance of efforts to support people back into training and employment. Limited capacity of dedicated services means that direct work with people with PD needs to be combined with efforts to support and train people in non-specialist services.

7.10.2 Evidence-based services

The evidence base to support the delivery of community-based services to people with PD is poor. While personal testimony of service users who participated in this study suggests that many people with PD can and do benefit from their contact with dedicated services, further effort needs to be made to establish optimal ways of working and those interventions that are most effective.

Randomised trial of Dialectical Behaviour Therapy (Linehan *et al*. 2006), Cognitive Behaviour Therapy (Davidson *et al*. 2006), Transference-Focused Therapy (Giesen-Bloo *et al*. 2006) and psychoanalytically informed psychotherapy (Bateman & Fonagy, 2001) for people with borderline personality disorder have demonstrated a positive impact on health and social outcomes. Clinical trials of Social Problem Solving (Huband *et al*. 2007) and CBT (Emmelkamp *et al*. 2006) suggest they may be helpful for people with other forms of PD. Data from evaluations of residential therapeutic communities suggest that this is also an effective approach to helping people with PD (Lees *et al*. 2004). Dedicated services for people with PD should be encouraged to continue to evaluate the impact of the work they do and to deliver interventions that are evidence-based. Quality of life, social functioning and level of mental distress are the outcome measures that service users and providers believe should be included in such evaluations. Consideration should be given as to how services that aim to deliver evidence-based interventions monitor the quality of the interventions they provide.

7.10.3 Timescale for service development

There is widespread agreement that it takes time, years rather than months, to help people with PD develop better ways of coping. Data from this study suggest it also takes time to develop successful dedicated services. Services that aim to foster peer support and deliver group-based interventions need time to allow service users to understand their approach to treatment and develop a culture that helps new users understand the model and provide mutual support.

7.10.4 The role of inpatient services

Many of the most important and valued services for people with PD in Britain have delivered residential treatment. Much of the learning that has enabled community-based services for people with PD to develop is based on their expertise. However, the development of community-based services has threatened these established units, not least because commissioners, keen to support continued funding of community services at a time of budgetary constraints, have argued that community services save money that would otherwise need to be spent on more costly inpatient treatment.

This study has not explored important questions about whether there is a group of people with severe PD who are unable to use community-based services and may benefit from residential treatment. However, we did explore the views of expert authors, and users and provider of services about priorities for development of services for people with PD. All three groups stated that the development of community services was a high priority and placed the inpatient services as the lowest priority. Given the consistent reports of improved health and social functioning reported by providers and users of these pilot services we believe that, in those areas where dedicated services exist, community-based treatment should be tried prior to considering the need for referral for inpatient treatment.

7.10.5 Role of voluntary sector and criminal justice system

Nine of the 11 pilot services that we studied were nested within existing statutory services. However, several of the pilots had developed links with the voluntary sector and one included funding to a voluntary sector organisation aimed at helping people access work and training. All the pilot services emphasised the importance of avoiding coercion and paternalism and supporting choice. We believe that services in the voluntary sector are well placed to deliver these approaches to helping people with PD and that future commissioning of services should explore opportunities for funding partnerships between statutory and voluntary-sector service providers. The voluntary sector may be particularly well placed to coordinate and support service user-led initiatives such as peer support groups.

Considerable uncertainty surrounds the issue of whether, and how, dedicated PD services can work with people with ASPD. If evidence begins to emerge that people with ASPD can be helped by community-based services, dedicated PD teams would be well placed to deliver these. Given that most of the costs associated with ASPD are borne by the criminal justice service, commissioning such services would need to involve partnerships between healthcare and the CJS.

7.10.6 Cost savings and cost-effectiveness

Previous research has demonstrated that people with PD incur health and societal costs that are much greater than those with other mental health-related problems (Perry *et al*, 1987; Knerer *et al*, 2005). Previous studies have also shown that interventions for people with PD can lead to substantial reductions in the use of emergency medical and inpatient mental health services (Bateman & Fonagy, 2004; Davidson *et al*, 2006). These findings are supported by audits conducted by several of the pilots showing reductions in the use of these resources. At a time of budgetary constraints, expansion of dedicated PD services may depend on their ability to demonstrate cost savings. However, as with other components of the healthcare system, consideration should also be given to improvements in mental health and quality of life and the cost-effectiveness of interventions delivered by such services.

7.11 Areas for future research

7.11.1 Indirect service provision

All 11 of the pilot services provided some tier one interventions and staff made a variety of suggestions about how these could best be delivered. However, we are unaware of any previous research that has tried to examine the impact of such interventions or compare the different approaches that are used. Anecdotally, service providers gave examples of instances where people who were being treated on inpatient units were subsequently discharged following case consultation. Those in receipt of indirect services told us they felt more confident working with people with PD. However, at a time when an evidence-base for the effectiveness of psychological interventions for helping people with PD is beginning to emerge, the impact of indirect service provision has not been quantified.

A recently published randomised trial of Social Problem Solving (Huband *et al*. 2007) suggested it is possible for people with limited previous experience of working psychologically with people with PD to be trained to develop an effective intervention. The relative impact of training people in general teams to deliver such interventions, compared to advice and support delivered by dedicated services, should be examined.

7.11.2 Direct service provision

Experimental studies should be conducted to examine the effects and cost-effectiveness of the approaches being used by pilots to help people with PD - notably day-TCs, DBT, case management services and service user networks. Further work also needs to be conducted to examine the effects and cost-effectiveness of residential treatment services for those who are unable to engage with, or benefit from, dedicated community-based services.

7.11.3 ASPD

We believe pilot studies combining qualitative and quantitative methods should be undertaken that would examine methods through which people with ASPD can be treated in community settings. Approaches such as day-TCs, nidotherapy and social problem solving have the potential to help people whose personality disorder is characterised by impulsivity and disregard for the rights of others. While there are likely to be major challenges associated with offering interventions to people with ASPD in community settings, and services may need to separate from those delivering interventions for people with other forms of PD, people with ASPD experience high levels of mental distress and social dysfunction and efforts should be made to see if it is possible to extend services in order to provide interventions for people with this disorder.

7.11.4 Prevention

Research is beginning to emerge that suggests parenting programmes and educational interventions can prevent the development of behavioural problems among younger people (Raine *et al*. 2003; Hutchings *et al*. 2007). Such interventions also offer the potential to reduce the incidence of personality disorder. Several of the pilot services are developing interventions aimed at parents: these offer the prospect of reducing the likelihood of the social transmission of personality-related problems. The Icebreak service in Plymouth also aims to intervene at an early stage in order to halt the development of inter-personal problems. Research into interventions that aim to reduce the development of personality disorder also need further evaluation. Such studies should adopt the staged approach to evaluating complex interventions and incorporate both qualitative and quantitative research methods (Campbell *et al*. 2000).

8 Conclusions

The development of the 11 dedicated services for people with PD appears to have been welcomed by commissioners, users and providers of local services. Dedicated services are seen as having the capacity to combine delivery of help with social problems, access to peer support and psychological interventions aimed at reducing emotional distress and improving quality of life.

There was widespread agreement about principles that should underpin service delivery, including the need for open communication, explicit boundaries, consistency and support for those who provide the service. Services need to be delivered over relatively long periods and to take time to help people plan their leaving. However, there is a lack of consensus about important issues such as the role of outreach and medication.

Service users praised the personal qualities of staff at the services and spoke of the value of peer support. Most told us that contact with dedicated services had helped them understand their problems better and change aspects of the way they feel about themselves and relate to others. However, concerns were expressed about assessment procedures and what would happen when their period of contact with the dedicated service came to an end.

Pilot services have succeeded in working with a substantial number of people with PD who have high levels of social dysfunction and suicidal behaviour. However, there are many people who are thought to be unable or unwilling to use services as they are currently configured. These include those who are very chaotic and people with antisocial personality disorder. Men were under-represented among referrals and those taken on by services.

Given the high prevalence of PD, services face the challenge of how best to use their limited resources; in particular the balance between direct and indirect service provision, and how much time they should invest in those with low levels of motivation at the expense of those who decide to try to use such services. Dedicated services may be able to increase their capacity by developing structures that provide peer support.

The long-term survival and expansion of dedicated services for people with PD will require the commitment of policy makers, and further evidence that intervention leads to improved outcomes and reduced use of other services. People with personality disorder are known to incur health and societal costs that are much greater than those with other mental health problems and if the cost of providing services could be at least partly offset by savings this could provide justification for further service development.

The 11 pilot services we evaluated achieved a considerable amount over a limited period of time. They appear to be delivering high-quality care to a group of people who have been poorly served in the past. We believe that the lessons they learned and feedback from service users can guide the development of new services for people with PD.

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Appendix 1

Detailed Case Studies

A1 Camden and Islington (C&I) Personality Disorder Initiative: 'Living and Working with PD in Camden & Islington'

1. Description of Services

Key to services

There are effectively three strands to this pilot initiative: Skills Development Service (SDS) provided to service users with PD by Umbrella (a voluntary sector organisation); a Training and Consultation Service (TCS), provided to organisations in primary care and the voluntary sector by Islington Psychotherapy Service and the Oscar Hill Service; and Community Links (CL), a primary care referrals facilitation service for service users seen by their GP.

1.1 Aims of pilot initiative

Despite the distinctions between the 3 service arms, the project is integrated in seeking to address the following gaps in the Camden and Islington catchment area (which covers an inner-city population of some 380,000):

- The absence of targeted support and management of people with personality disorder in primary care and the voluntary sector – in particular for young people in contact with health and social care services;

- Limited training opportunities to develop specialist skills for working with people with personality disorders in primary care and the voluntary sector;

- The absence of specialised, targeted vocational support for people with personality disorder;

- The absence of effectively focused day services;

- Limited capacity of CMHT staff to support people with personality disorders;

- Poor coordination between services and inadequate care pathways for people with personality disorder.

By:

- Improving the access to relevant interventions for people with personality disorder in primary care, social care and the voluntary sector;

- Enhancing the capacity of primary care and voluntary sector services to provide appropriate, non-stigmatising interventions and services to people with personality disorder. [Extracts from Bid]

The service arms described above have organisational links, through the coordinating role of the head of the Oscar Hill Service, who was funded for 2 sessions per week to fulfil that role. The links have been further developed through the establishment of a personality disorders network. The Oscar Hill Service (OHS) was established 1999, it provides assessment and treatment for people with personality disorder using Dialectical Behaviour Therapy. Core funding for the Oscar Hill Service is not from pilot money.

1.2 SKILLS DEVELOPMENT SERVICE (hosted by Umbrella)

1.2.1 Specific aims of the service

The Skills Development Service (SDS) aimed to provide vocational support to 50 service users per year and to place an additional 20 into supported employment. The bid states: *'Interventions focusing on employment and related activity may contribute to a reduced need for specialist interventions from secondary care services'*. Cost savings, reduction of stigma and of dependence associated with use of mental health services, and social inclusion are stated aims.

1.2.2 Staffing the service

There were initial concerns about employing staff inexperienced in working with this client group: Managers now feel the lack of preconceived notions was helpful, although training was time-consuming. Three Skills Development Workers (SDWs) were recruited in October 2004, and one manager shortly afterwards: all received comprehensive training delivered by OHS staff which took 3-4 months. An ex-service user is employed on same basis as the other workers. Two of the workers have psychology degrees, one was a dance movement therapist, the skills development service manager has an art therapy background. The initial proposed salary level was raised to attract *'young, bright, social science graduates'.* Training and development (led by the Oscar Hill Service) covered the identification of PD, some principles of DBT and motivational interviewing. Training around accessing courses, occupations, careers advice, and vocational assessment was also given by an external provider. SDS workers interviewed had up to 15 service users on their caseload, with the manager playing an active role in assessment and supervision. The team was all female when visited, though this has since changed to 2 male and 2 female, one of whom is from an ethnic minority. They did not have direct forensic experience, although they do take referrals from probation services. Expectations of the service user group and work have developed since the service began. Staff commented that more training on Antisocial Personality Disorder would have been useful, as anti-social traits are commonly encountered. The initial brief for the SDW posts was to have one SDW specialising in each of 3 areas: literacy and numeracy, general vocational support and career counselling. Referrals did not justify the emphasis on basic educational skills. It was also found that work on motivation took longer than expected, with service users taking months of counselling to reach the stage of needing specific career and employment support.

The team meets with the organisational consultant (see below) fortnightly. *'It's not that she gave us any answers but she allowed us space to think about our anxieties around it and I think that's useful.'* The OHS training was followed up by some joint working initiatives in a group format to build on the training provided. The team share a single office, so informal debate is ongoing, and there are weekly check-in and fortnightly staff meetings, as well as supervision with their line manager (who works from the same office).

1.2.3 Client group and referral process

Criteria for the SDS are being aged 18+; having a GP in the boroughs of Camden and Islington; either diagnosis of PD or persistent recurring relationship difficulties resulting in social exclusion. Exclusions are: a primary diagnosis of psychotic illness; high risk of self-harm if NOT supported by Mental Health services; primary problem which might interfere with benefit from SDS (e.g. substance misuse; homelessness) especially if not being treated by health services; current risk of violence. However, the service does work with service users diagnosed with ASPD.

The local day hospital is the primary source of referrals; followed by one particular CMHT, the psychology service of the Care Trust, Graduate Primary Care Mental Health Workers, and the local crisis centre. SDS does take self-referrals. Service users must agree to contact with their GP or another healthcare contact as fall-back if SDS is worried about them. Each referral is individually considered, with capacity to work with and benefit from the service being critical. All service users are assessed by two members of staff, usually with the manager as one member.

The gender mix of SDS service users is almost 50/50 (in contrast to the OHS where the majority of service users are female). While formal assessment of the type of personality disorder that service users have is not made by SDS, information from referrers suggests that this incorporates a range of types of PD including borderline, anti-social and avoidant PD. SDS have had referrals of people from black and minority ethnic communities of approximately 14.5%, which is representative of the local community. They have also taken on service users with mental health problems in addition to personality disorder. Service users are older than expected in the bid: they tend to be over 30, average age early-mid 40s, and out of work a long time. 'One might not necessarily think about where they're at 25, but they're more likely to at 35.' Many service users referred have substantial forensic histories. This has raised some anxieties within the team. Although about 50% of SDS service users have care coordinators within the framework of CPA, accessed from local mental health teams, others have been unable to access such services 'the people we see are often the ones that no-one else is doing much with at the moment.'

1.2.4 Model of intervention, expected outputs and outcomes

Skills Development Service (SDS) is specifically for service users with PD: its parent organisation, 'Umbrella', delivers a wide range of support to people with MH problems who are socially excluded. SDS offers:

- 1-to-1 support sessions;

- Personal development groups (Getting along with people; Stress management; Motivating yourself; Life enhancement; Finding your direction);

- Practical Groups (Time Management; Job or course searching; Disclosure; CV-writing; Interviewing skills; Welfare rights/benefits; Identifying your field of interest).

SDS generated referrals by visiting CMHTs, day hospitals, supported housing, etc. As in the Community Links service (see below), PD has been replaced by 'interpersonal problems' in its publicity as it is felt this is more acceptable to service users and to GPs wishing to refer. This may mean that some referrals do not have PD: staff feel that GPs require more training in this area.

SDS engagement starts with assessment. Assessment covers: 'Previous work, background, college background, education, skills, hobbies, what they like doing, what they don't like doing: even if it's 30 years ago, I'd have grasped something that they have enjoyed in their lives. What they're currently doing as well... what barriers they see might come up, if they might have problems getting up in the morning, working on how to overcome that. So it's really finding out where people are at, and where they'd like to be.' SDS does take people not interested in work, as long as they acknowledge desire to increase structure in their lives. The service user is allocated to one worker. Goals are negotiated, and a timetable of review and attainment is constructed. The worker tends to see the service user once a week or fortnightly, but can be flexible. People come in wanting 'a shift in their life': Staff report that, about a month into the sessions, it becomes more challenging and more difficult to move forward, and the service user may encounter 'period of stuckness': and disengage. . 'Sometimes the aim can be to find an aim, some people are just so lost…' Moving away from dependence on benefits is a key issue: 'It's very difficult to go from benefits to wages, because if something goes wrong … And so one of the things that we really try to reiterate is that it's people's own steps and their own pace….[the]mental health system can be very much suppressing, and damning of, any hopes and chances.'

Supporting these service users – many of whom spend a lot of time isolated at home – may not lead to great cost savings in the NHS, since they are primarily avoidant of, or do not have access to, services. However cost savings to other agencies could arise from increased numbers of people in work. Service users remaining in the service for 6-12 months are starting to progress, working on CVs, and looking at jobs. SDS acknowledges problems in getting people to attend appointments. Group attendance was initially difficult to establish, probably as a result of social anxieties of this client group. This problem was overcome through problem solving in individual sessions and subsequently groups were successfully established.

When people were engaging in group work, the contact time for an SDS service user would probably be 1.5 hours for 1-to-1, and 1.5 hours per week for each of 2 groups, a total of 4.5 hours per week, but this would be in preparation for the assumption of longer working hours.

The method of working is designed to discourage dependence and increase self-agency, independence and self-responsibility. 'It's a two-way partnership. It isn't about us doing things for them, it's actually about us supporting them to do things for themselves, so there needs to be commitment there. And the commitment would be to attend meetings even when feeling not well: that's when our work really begins, so that we can support them through it.' 'We're looking at the positive side, we're looking at their capable side without ignoring their vulnerable side … so you're validating all sides to people and I think that's what mental health support should be doing…' SDS staff consider it important that all parties liaise: in the event of concern about the service user, support would be sought from the care coordinator or GP. SDS workers may well see service users more frequently than the care coordinators do and may therefore be a source of current information about their welfare.

Two levels of group work have been planned: step one targeting skills deficits arising from personality difficulties; and step two practical vocational skills. Eventually, the SDS plans to develop links with employers, and provide ongoing support to both service users in employment, and to employers who agree to take on people with such problems. Provision of ongoing support when people do find work or education is a key part of SDS remit which it hopes to develop during the life of the pilot. An advantage of vocational work is that 'people don't have expectations of us, that we will take the pain they are feeling away. It feels a bit less stressful' (than working in crisis services, as she did previously). The service sees itself as complementing and co-working with mainstream mental health services. Its services are generally limited to office hours (although planned evening appointments are available). Space for group work is at a premium, staff may need to decamp to another building to find space for a one-to-one interview.

The team feel they underestimated the degree of disability experienced by this group (often long-term unemployed), as well as the extent of their psychological reliance on benefits. There has been turnover in the team which has allowed for the recruitment of 2 men, which corresponds with the 50/50 gender split of service users. The service feels that the optimum capacity of the service is 50 service users and that the original expectation to work with an additional 20 in supported employment was over-ambitious.

SDS took presentations about their new service around CMHTs, supported housing facilities and day hospitals to publicise the service, but has no regular commitment to provide training. The team has completed the North London, NIMHE funded 'Training the trainers' PD programme, and delivered the training to other Umbrella employees. The key area of training the team wants to progress is the delivery of mental health awareness to employers, as this will expand work placements.

1.4 COMMUNITY LINKS SERVICE (CL)

1.4.1 Specific aims of the service

The Community Links service is an extension of a previously evaluated primary care brief intervention model. Community Links, also known as "referrals facilitation" or social prescribing", aims to provide information and link people in with a range of community resources – leisure, educational, vocational, supportive or therapeutic – that might support their psychosocial needs. Service users are often also directed towards benefits, housing or financial advice where appropriate. The original service was expanded to include service users with 'interpersonal problems'/personality disorder, which may address their needs without recourse to stigmatising mental health services.

1.4.2 Staffing the service

The service is delivered by up to 6 graduate primary care mental health workers (GWs), offering short problem-solving sessions (up to 6) for service users referred by their GPs or other primary care staff. The workers offer sessional services to 19 primary care practices in Camden, 25 in Islington. Only two of these workers are funded by pilot funding, but all 6 are working with service users with both types of problems (PD and affective disorders), to improve access to the service across the 2 boroughs .GWs have had 4 half-day training sessions in PD-related issues, a 3-day training session on CBT-based guided self-help, and are required to complete a Post Graduate Certificate in Mental Health in Primary Care during their first year in post. The PD training was delivered by the OHS component of the Training and Consultation Service and included:

- The identification, prevalence and aetiology of personality disorders

- Interpersonal and clinical issues associated with a diagnosis of PD

- Issues related to social exclusion and stigmatisation of individuals with this diagnosis.

- Therapeutic principles for the engagement and management of people with a PD diagnosis/significant interpersonal problems in the context of a brief intervention

- A focus on specific skills including: validation, contingency management, problem solving versus acceptance and limit-setting

Along with specific topics suggested by GWs on:

- Therapeutic strategies for avoiding power struggles with service users

- Maintaining professional, personal and organisational boundaries

- Engaging service users who appear de-motivated and non-collaborative or whose needs exceed the stated aims of the intervention

> ▪Avoiding becoming personally demoralised in the face of the above

This training is followed up by a fortnightly specialist supervision group which focuses on their PD work in addition to weekly supervision with a clinical psychologist, The group supervision is clearly highly valued by the GWs, but the dispersal of the workers and their different commitments has occasionally caused problems in delivering it. The programme will probably need to support a rolling staff of GWs, with a consequent investment in training, because of the tendency for workers to deliver the service as part of a longer-term career plan.

1.4.3 Client group and referral process

The service depends on referrals from primary care staff, and experience has shown that they tend to have limited capacity to distinguish between service users with mood disorder and personality disorder. For this reason, the same GWs see all those referred who attend, and decide during assessment whether the person is best suited to CBT-based guided self-help (primarily aimed at service users with depression, anxiety, panic etc) or to Community Links. Referrers (practice staff) complete a short form which asks them to specify which service they are applying for, and are also asked whether the person has 'interpersonal problems'. Referrers are not always discriminating, so the PCMHWs themselves, in discussion with their supervisors, make this distinction and decide both on the intervention and the length of contact offered. 'Perhaps they think there's a slightly higher threshold for the service: if they don't tick all the boxes, the person doesn't get help.' This service aims to pick up service users who are not accessing mental health secondary care, and would exclude those with a major mental illness, but may occasionally take those attending CMHTs for medication only.

1.4.4 Model of intervention, expected outputs and outcomes

The CL service is provided as part of a stepped care model. Workers have training in mental health (see above) and specifically in personality disorder, with specialist support and supervision from the Oscar Hill Service, in addition to the regular clinical supervision they receive. Service users are supported to access a wide range of community resources and services within health, social care, education, leisure, counselling and advice areas that may be of use to them. Access may be facilitated by matching need to services, information, referral, motivating the person to apply, and at times by accompanying the person to the first contact.

The original service for people with affective disorder aimed at 2 +1 sessions: assessment, followed by provision of information around services / problem-solving and motivational work to encourage attendance, followed by a follow-up session. Service users thought to have PD who have been offered the Community Links service may be offered more sessions – up to six - in order to facilitate engagement. Although the service is not aimed at those in crisis, concerns around service users may arise in the course of the sessions and are referred directly to GPs or crisis services. There are issues for some service users around disengaging from the service, although it is made clear that the intervention is short-term. CL can refer to the voluntary service Skills Development Service (above), but two workers voiced frustration that they cannot refer directly to the Oscar Hill Service for psychological therapies without the intervention of a CMHT. One clear remit of the primary care location is to avoid channelling people into secondary services that do not meet their needs.

Workers are 'attached' to (and in some cases, co-located with) particular GP practices, and the training and supporting of GPs to recognise and refer service users with PD was integrated with the publicising of the service (with appropriate leaflets). The response from GPs has been variable: some have resisted the use of the PD 'label', while others have appeared enthusiastic but do not necessarily refer, and the rate of referrals has been unpredictable. Workers tend to have minimal waiting lists because of the short-term nature of the intervention, although one did comment on having to remind himself of the need to justify additional sessions, since service users may want to continue in the service, and may be better suited by referral on to counselling services.

1.3 TRAINING AND CONSULTATION SERVICE (TCS):

The training and consultation service has two components; to provide training and consultation to voluntary organisations working with people with PD and to staff in primary care teams including the graduate workers appointed to the community links service.

1.3.1 Specific aims of the service

With respect to the voluntary sector TCS has aimed implicitly to promote the development of healthy organisations and explicitly to help individuals and teams to work more effectively with people with PD. In this context healthy organisations are considered to be those that have

- Clarity about primary tasks;

- Clarity about hierarchy of roles and responsibilities;

- Clarity about the way the work is done.

- An acknowledgement that the work impacts on the worker.

With respect to primary care the TCS has aimed to enhance the capacity of the primary care team in recognising and managing PD as it manifests itself in primary care.

1.3.2 Staffing the service

The TCS is run jointly by the Islington psychotherapy service and the OHS. The staffing component is 0.7 wte of an organisational consultant who's been in post since January 2005 supported by an additional one session of management time from within her department. 1wte post is based at the OHS divided between 3 people. Two of these have a psychology background and one has a nursing background.

1.3.3.Training and consultation to the voluntary sector

Organisations and teams are clients of this service. As of June 2006, 21 organisations had been approached, 16 had taken up or planned to take up training or consultation, 5 organisations were in receipt of ongoing consultation, while 7 were awaiting planned training programmes. 6 organisations had taken between 6 months and a year to take up training, whereas 10 did so within 6 months of the exploratory visit. Client organisations are generally members of Camden and Islington Provider Forum (CIPFA). Many of these organisations provide supported housing or floating support to people who would meet criteria for a diagnosis of personality disorder. Some work with service users with mental health, forensic or substance misuse histories. One was a suicide prevention service and another a women's counselling service.

The eventual focus of the options offered by the TCS is the management of service users with PD; but the consultation as opposed to the training aspect is also directed at dysfunction within the organisation itself. Organisations can select from a menu and address either or both of these areas.

There are four possible components to TCS:
- Diagnostic event: team comes together with the organisational consultant to reflect on what could best support them in their work;
- 5 day training event delivered by staff from the Oscar Hill Service for frontline workers on recognising and working with PD.
- Short Course Intervention developed by the Tavistock Clinic and franchised. (10x2 hour weekly sessions aimed at unconscious processes affecting team functioning: can be taken in whole or half-days);
- Consultation (which can also be delivered as follow-ups): can be team/group discussion(s), but can also be 'role' consultations, perhaps one-to-one.

The Diagnostic Event is an opportunity for an organisation to check their understanding of personality disorder and what training and consultation supervision they could benefit from to increase their capacity to work with people with PD. The entire team should be involved, including for example, in a hostel for the homeless, the cleaners. The model for a healthy organisation (see above) comes from the Short Course Intervention and can be used as a template against which the organisation can reflect upon itself. 'It's a multi-layered day: I start with giving them a chance to say something about their experience.... They talk to each other in a way they may not have talked to each other for months, if ever and then I move on to getting them to begin to use their minds and think about the structure that supports the work of the organisation, basic operating principles, that's the second layer. So you've got quite a bit of information beginning to filter through about where the struggles are and where things are working well. I then move on to a small group exercise where they'd begin to explore what best supports them'

The Oscar Hill training is a DBT-based model of personality disorders, and how strategies for management of PD service users can be developed. The training on offer does not train workers to deliver the therapy, but it does draw on the DBT model for understanding personality disorder and teaches some practical skills from the model which can be useful in working with clients with personality disorder.

The training menu includes the following topics:

- Recognising personality disorder

- Validation and setting limits

- Increasing collaborative behaviour

- Maintaining effective relationships

- Reinforcing positive behaviour

- Risk assessment and management

- Managing your own emotional responses

The Short Course Intervention provides a model for organisational functioning within which workers have a place to think together. It is said to be particularly useful for organisations where staff are largely unqualified, ie have no training in a particular discipline but it's also useful for qualified staff too, because it provides a shared model for thinking about the work. The Short Course Intervention is designed by the Tavistock Institute and comes with a pre- and post- attitude questionnaire, largely based on asking people about their relationships with colleagues, service users, wider organisation, society's perceptions, etc. 'The course is a mix of lectures and participatory seminars comprising 10 sessions, building on human development, how groups and organisations function.

Consultation is probably the least structured and therefore more exploratory intervention offered. 'One of the main theories about personality disordered people is that they don't have the capacity to reflect on themselves and so if (they are involved with) an organisation that equally can't reflect, you're going to have this sort of mirroring that goes all the way up from the client themselves all the way up through the organisation that's trying to help the client… Services may be set up without taking into account the need for this self-reflective space: it is often seen by management as an unnecessary luxury.'

1.3.4 Training and consultation to staff in primary care:

This aspect of the TCS was delivered by staff from the OHS and involved training on the theme of "PD in primary care" to GPs, Practice Nurses and others working in primary care. The initiative drew on the DBT model. This was advertised through written material sent to each practice and so far 10 practices have received training and consultation (approx 10% of GP practices in C&I)

The training and consultation strand of the C&I initiative was designed to enhance the skills and capacity of the primary care and voluntary sectors to support people within the community in primary care and the voluntary sector to manage potentially quite difficult people. The expectation is that this will reduce referrals to secondary sector specialist services. Some of the other pilot services have expressed interest in using the TCS service for consultation. The service appears to be very well received, not least among other pilot services, and is in danger of encouraging demand that can't be met.

2. Achievements and capacity of service

The SDS model is a model of engagement which constitutes a form of therapeutically oriented psychosocial support incorporating both DBT and psychoanalytic elements. It is an innovative service in which the model used is led by experience *'the team's confidence is growing and skills growing and they've been instrumental in putting together the skills group material themselves. This was really fundamental in terms of what the service was going to be about and who we were going to attract.'* In the 18 months to June 2006, 130 referrals were received, of whom 74 accepted and engaged with the service. 22 service users have gone on into work or training placements. A further 56 were offered assessment appointments, and either did not show, were referred on, or input was successfully terminated.

TCS has found that some organisations easily lose clarity about primary tasks, but are reluctant to acknowledge this, and that service users absorb this. Consultancy and training support the maintenance of focus on the core task. This is an innovative approach, and it may be difficult in the long run to persuade commissioners that it is achieving resource savings. Feedback from the other pilot services suggests that organisational support is one of the key areas that they struggle with. The TCS model expects that follow-up sessions will be needed to sustain impact. The training and consultation aspect of the bid is consistent with NIMHE guidelines that working with PD service users can have a negative impact on individuals and teams (and, further, that dysfunctional teams may deliver poor outcomes for service users).

The CL service has achieved wide coverage of primary care practices in two large boroughs, although referrals do depend on the awareness and receptiveness of GPs. The target (as specified in bid) was to deliver intervention to 80 PD service users p.a., and this has surely been achieved although it is not straightforward to disaggregate those with PD from service users whose affective disorders are not linked to personality. It is likely that the service has raised awareness of PD and competence in identifying people with these problems.

All three services aim to reduce stigma through care pathways that are not necessarily linked to secondary MH services or to 'diagnosis'. All three services have engaged with a significant number of health and social care services and delivered substantial amounts of training.

3. Departures from original specification: drivers & impediments

The multifaceted nature of the bid was an outcome of the local context: the geographical area was large and there was a range of existing services working with people with PD so that services were in danger of bidding against each other. An attempt therefore was made to develop a multi-agency partnership bid. Monies were paid directly to Islington PCT, then to the Care Trust who were then invoiced by Umbrella.

There is no current evidence base for the emphasis on providing vocational skills to people with PD. The project does, however, (as London bids were asked to do) provide enhancement of the voluntary and primary care sectors. The SDS did not aim to target the most needy service users (who would be unlikely to benefit from employment counselling). The Care Trust TCS initiative has benefited from collaboration. A team focused model of training is that recommended by NIMHE.

Vocational support staff in SDS have discovered that long-term work is necessary with many service users: and it is difficult to plan long-term goals when pilot funding is time-limited. Small numbers of staff and the long term nature of PD mean that throughput is slow. Employment as an outcome can also be difficult with benefit recipients because the cost of London accommodation is so high, and housing benefit so critical. It has also been difficult to identify the 'right' client group for the vocational services – both within SDS, and within primary care, where GPs have little understanding of distinctions between PD, affective disorders and social exclusion. SDS is one of many voluntary sector services in the area offering vocational support: they have had to publicise themselves and justify the 'PD' aspect to referrers and commissioners. The perception of attached stigma has had the effect of making services – including GP practices - very cautious about language, labelling, and relationships with MH services.

The Community Links service based in primary care has not established a discreet service for PD service users, but has integrated this group into the existing service for service users with affective disorders. This adaptation was driven by the need to 'attach' workers to practices over a very wide area, which made it impractical for individuals to have different remits. It has also enabled workers to acquire broader training and experience to assess and provide services to both groups. It also makes sense in primary care where there may be less clear differentiation between affective and less severe personality disorder.

Overall, the C&I projects were to be overseen through coordinating management and governance structures: the convening of a personality disorder reference group which would comprise all key agencies and stakeholders in Camden and Islington: a coordination group for the programme which would meet on a monthly basis and involve staff from all 4 contributing agencies; and the development of a care pathway and service coordination group across the voluntary, primary and secondary care services in Camden and Islington. The operational group, chaired by the head of the OHS, representing the three components SDS, CL and TCS meets fortnightly to plan interventions and to coordinate the services. A multi-agency steering group has met regularly (currently on a two monthly basis) its remit to formulate a local PD strategy and to work towards developing a managed clinical network for PD. This group includes a local MH commissioner, and the Care Services Improvement Partnership (CSIP) PD lead for London.

4. Findings from local audit and evaluation

Local evaluation of the SDS shows that social functioning improved for service users. For the service users who completed a follow up questionnaire at 6 months, there was a mean reduction in the Social Functioning Questionnaire score of 1.45 (on a scale with a maximum score of 18 indicating severely impaired social functioning). The maximum reduction was a drop of 5 points. One service user increased by a point. There was also a reduction in use of other services. There was an overall reduction in people seeing a psychiatrist once or more in the last 6 months of 32.5%, reduction of ED and hospital admissions of 10.4% each and a drop in visits to the police of 11.4%.

It is difficult to demonstrate and measure the outcomes of the training and consultation service. However with respect to the DBT-influenced training, pre- and post- questionnaires measuring knowledge and attitudes to PD were administered, indicating a mean improvement after the training.

Within Community Links a small semi-structured interview study was conducted involving 12 service users providing useful feedback. An external researcher contacted service users who had used the service. Many gave positive feedback and some gave mixed feedback. 58% felt their problems had improved since receiving the intervention, while 33% felt that their problems had got worst as a result of environmental factors.

5. Summary of lessons learned by service providers

- People with PD in primary care are a heterogeneous group whom primary care workers tend not see as having this disorder. They are difficult to engage, have often had unsatisfactory experiences of services, and some may experience brief intervention as inadequate.

- High levels of impairment and social avoidance meant that the duration of intervention delivered by voluntary sector workers had to be longer than initially envisaged.

- The culture of the voluntary sector may be more readily accepted than that of the statutory sector by people with PD who are males or from BME communities.

- Enthusiastic, but relatively untrained, voluntary sector staff can work very effectively with difficult clients if given training and support from specialist mental health services.

- Training and consultation is a useful vehicle for networking different parts of the care system.

- Absence of management support leaves some workers in the voluntary sector very vulnerable in face of extremely difficult clients.

▪There is a challenge involved in achieving respect for professional difference across organisations, and working towards collaborative rather than competitive and conflictual relationships. This is made even more difficult because of increased competitive pressures resulting from changes in commissioning of services

6. A Summary of Service Users' Views

We interviewed nine people linked to the Umbrella service in Camden and Islington: seven current service users (three men and four women) and two carers. Interviewees had been in contact with the service for between six months and three years; they had used the groups, skills development and one-to-ones. Site staff identified potential research participants who were then contacted directly by the service user researchers.

Information and expectations

Interviewees were drawn to the service by the fact that Umbrella is vocationally oriented; all but one came to it for this reason and the remaining one, who had initially wanted a housing service, came back to Umbrella for vocational help.

Relationships with staff

The quality of the staff was a key feature of Umbrella. All service users described staff in positive ways: for example, as non-judgemental, friendly and supportive, reliable, flexible, understanding and willing to take things in small steps. In addition, they said that staff were interested in helping them to achieve what they wanted and were outcome-based in their approach. Several people mentioned a lack of continuity amongst staff due to maternity leave, although not usually in a negative sense.

Relationships with service users

Some service users had found it helpful to be with other service users, because it made them realise that their difficulties were not unique, it was a means of support and it was helpful to hear how others dealt with things. However, quite a few said that they had little contact with other service users. Whilst not everyone would have been comfortable in a group, a few expressed specific concerns about having little contact with others or of wanting more or longer groups.

Involvement

All current service users talked of having support plans and indicated that they were very much in control of the support they received. Conversely, several said that they had no say in the overall running of Umbrella; a couple of people said they would like to have more involvement in how it was run.

Outcomes

All service users thought that they had made achievements through coming to Umbrella, and all mentioned vocationally-related gains: training, voluntary work, ideas for a job, a job interview, a work placement and an offer of employment. In addition they mentioned increased self-awareness, improved relationships, managing feelings better and changes in behaviour that enabled them to move towards voluntary or paid work.

Carers Perspective

Both carers also spoke positively about the effect of the service on the person they cared for, although one felt that carers could be more actively involved in, for example, attending meetings or receiving relevant information – if a service user wanted this.

Facilities

A few people were concerned that the location was not ideal for Camden residents and that the office was too cramped and noisy and lacked printing and internet facilities.

Clarity and structure

A couple of service users felt that the service needed to have clearer aims and procedures, including clear information about who is eligible to use the service (their impression was that Umbrella had recently opened out its services to people with major mental health problems). There was also some concern about the referral process: that it was unclear or that information was not readily available or that information was misleading (giving the impression that there was more available at Umbrella than there is).

Diversity

A couple of people expressed concerns about the ability of staff to deal with the diversity of people using the service; in particular, they mentioned the staff response to racist comments made by a service user in a group session. They felt that staff would benefit from (more) group work training and that the organisation needed to introduce anti-discrimination measures such as a written policy and procedures.

A2 Dual Diagnosis Assessment & Response Team (DDART)

1. Description of Service

1.1 Aims of pilot service (from SLA and bid)

- To provide a specialist psychological therapies service for individuals with a personality disorder and co-morbid substance misuse, working in partnership with staff from statutory and independent sectors;

- to support staff working in health and social care agencies and encourage new models of integrated working;

- to facilitate creation and implementation of integrated health and social care plans;

- to provide training, supervision and consultation framework for consistent interagency working;

- to provide full assessment of service users with Cluster B or C PD who substance misuse;

- to create comprehensive formulations of the complex needs of such service users;

- to facilitate pathways into or through care via motivational enhancement, consultation and advocacy as needed;

- to provide intensive specialist treatment for a subset of service users.

The SLA suggests individual outcomes of 35-50% reduction in frequency of self harm during first year of treatment; and approx 30% reduction in substance misuse (abstinence for six months, includes compliant drug replacement use).

1.2 Staffing the service

The team employs professionals from a range of disciplines (including nursing, occupational therapy, psychiatry and psychology) all working as psychological therapists providing DBT, CBT, and motivational enhancement. As of June 2006, the staff team stood at 8 (7.5 FTE), including two clinicians who were also senior managers and an administrator, with 2 posts (for social worker; for psychiatrist sessions) vacant. Premises and management are shared with the IMPACT team (a team of 6 for PD service users without substance misuse problems, with whom DDART merged in mid-2006). The service offers training placements for clinical psychologists, counseling psychologist, and specialist registrars. As of June 2006 the service had one clinical psychology trainee and one specialist registrar (three sessions).

The team has a clear and comprehensive system for providing staff supervision, which in several ways parallels the supervision and support of service users. 'Clients unload emotion on you, so you need supervision to deal with that so you are not overwhelmed'. Consistent with the DBT model, sessions with service users are tape recorded for supervision. The team believe it is vital for containment of staff – and ultimately of service users – for staff to subscribe to an 'open, honest communication style: so (they need) an ability to say "oops, I don't know what I'm doing" or "gosh, I made a mistake"'. The entire caseload is reviewed by the team every week in the DBT clinical review, DBT consultation meeting, and the non-DBT clinical review meeting. In addition staff receive regular one-to-one DBT, Motivational Interviewing, and CBT supervision (using recorded sessions). The organisation of the team is around two key managers, who can be contacted at all hours by staff. The managers and other staff can also be contacted in extended hours by service users in DBT. This is unusual (although it was felt to be the most effective way of delivering out of hour support required for service users in DBT). The consistency of top-down management by two seniors who make sure they agree, as well as the decision to have no middle management, is deliberately reinforced to prevent staff splits. While feedback from staff suggests the team is well-contained, supportive and supporting, it is not clear whether this structure will be able to continue if the team expands, as appears likely. New coordinator roles within the team have been developed to delegate some of the management tasks to facilitate the roll out of DDART to two more boroughs in 2007.

DDART managers admit to early mistakes in the staff recruited. Initial staff found the client group difficult to work with, lacked the fundamental therapeutic skills needed to engage and contain the client group, and found the intensity of supervision threatening. The policies and procedures of the service have been developed from within the DBT model. This model provides the principles of the service. However, some staff have felt overly controlled (less autonomy) working in a strong model driven service, while others have found this to be liberating and containing. Because of the workload (this is a small team), there is little time to debate existing systems: what is needed are 'staff who are comfortable with systems and don't feel a need to develop systems'. Staff need to be human, and to learn from human error. 'If you want to be the perfect professional, don't work here: clients need to use us as a resource, take from us: if you can't open up to colleagues, it will build up.' Basing the subsequent round of recruitment on personal qualities has placed heavy demands on the service for (largely internal) training and supervision and clarification of the model. One of the important themes of supervision appears to be that staff should not feel guilty because of the limitations of what they can do for service users: 'we don't have to meet every one of their needs and we don't have to feel guilty that they're in pain. They've been in pain for many, many years without us and that they will feel better one day.' The system of supervision enables staff to manage anxieties arising from work with a risky service user group, as well as anxieties generated by learning and using new therapy skills.

1.3 Client group and referral process

This service is part of North East London MH Trust (NELMHT), and is for residents of London Borough of Waltham Forest, from Chingford to Leytonstone: but also has strong links with London Borough of Redbridge, where it is housed in Goodmayes hospital. (The service shares management personnel, philosophy and location with the IMPACT Team, which operates in both boroughs, and takes similar service users for whom substance misuse is not a primary issue: by April 2007, the teams will merge to take on the name IMPART.) Satellite rooms are provided at the Larkswood Centre (for better access of service users living in NW region of catchment area) and South Forest Centre (for service users in the SW sector of the borough). The service works with service users with a PD diagnosis within B or C clusters, but will exclude those with cluster A PD or only ASPD because there is no evidence base for the effectiveness of the service models of therapy in people with these problems. Assessment is ordinarily curtailed if this conclusion is reached (not least to minimise attachment), and a recommendation for forensic, outreach or other services is made. Service users for DDART should also meet DSM IV criteria for substance dependence, though there is some flexibility around this: for example, people who abstain between twice-monthly binges are not excluded from the service. Those exhibiting recent or severe violence are excluded on grounds of risk, and service users have to have some motivation to engage: those attending by court order alone are not accepted, although some do have Anti Social Behavior Orders. Service users who commence assessment but choose to leave without completing the assessment or planned treatment can be re-referred or self-refer at a later date.

DDART accepts service users from age 18 to older adulthood. DDART accepts service users with a learning disability if they have the capacity to understand and consent to treatment and to work collaboratively with staff.

1.4 Model of intervention, expected outputs and outcomes

The aim of the service is to assist service users to maximise their potential and to build 'a life worth living'. The DDART service has been developed within the principles of DBT. All service users received a period of motivational enhancement at the start of treatment to encourage consideration of the reasons for change and obstacles to change. The service is recovery focused with an emphasis on increasing occupied time, quality of life, and maximizing personal potential. The service offers flexibility for service users in order to accommodate these goals including evening and weekend sessions.

DDART offers a comprehensive (structured) assessment for diagnosis, need and treatment history. This assessment requires 12-16 hours of assessment time to complete. A comprehensive formulation is then derived from the assessment with an awareness of Maslow's hierarchy of need that psychological change cannot occur if basic needs are unmet. The formulation allows for the generation of complex treatment recommendations for all services involved (including GP and voluntary sector) so that the service user is receiving a comprehensive but planned package of care. As well as DBT (substance misuse version), therapies offered may include motivational work and CBT, but in all cases, service users are expected to take a very active part, e.g. by being aware of the type of therapy they are undertaking, and keeping diaries of their emotional states and strategies. Service users entering treatment sign a contract signifying, among other things, permission for services to chase them if (as is relatively common in therapy contexts) they fail to attend. The contract can be adapted to promote or discourage specific past behaviours. The team does not offer full case management except for limited periods (and may advocate for the service user with other providers), but does identify unmet need, help service users to consider other options and referrals, and works with other services to facilitate individualised care packages. Formulations are shared with service users, and goals and targets for therapy are negotiated and reviewed regularly throughout treatment.

DBT is a two stage model: in stage one risk behaviours are reduced, Axis I disorders (including substance misuse) improved, and quality of life improved. In Stage II of DBT service users are invited to work on PTSD, shame, blame, guilt, and schema change, thus the work on causes follows the work on immediate concerns of risk and quality of life. The DBT model in which the team specialises has a very clear rationale: it is used with people who show emotional dysregulation, whose coping strategies include substance misuse, and is initially aimed at the development of alternative coping strategies. No work on the causes is done unless and until the potential risk of self-harm is acceptable, because of the likelihood that emotional stress will increase leading to an increase in impulsive risk to self and others. (Few of the other pilot services insist on this distinction.). 'We very much deal with here and now. Before you can start going into the past, people must have skills to deal with emotions, otherwise you increase risk.' The type of therapy offered is always flexible and service user-led.

'Everything's got to be goal focused. And if the client doesn't come in at a level where they are ready to set goals, then we have a therapy goal and that is to engage them, to have them attending regularly or to be exploring what goals they might want to set. The underlying theme is they come here for change, we're not a maintenance model, we don't want people to come here just to attach to us and be comfortable. We want people to move on and have a life worth living: therapy is just a tool to move on: what is it that you need to change so that you can have the life that you want to live?'

When a treatment formulation is prepared, a professionals' meeting is held with referrers and others involved with the service user to establish a unified care package and identify the training and supervision needs of staff. Case management is shared with the referring team, who manage the non-psychological therapy part of the care package. Although there is variation between different treatments, service users starting DBT draw up a 12 month contract in the first instance.

DBT clients have both an individual and 2 ½ hour group session each week. A maximum of 8 people enter DBT groups. One-to-one sessions are used to review behaviours which might have occurred, to review the skills that were utilised and to reinforce strategies and explore options.

By December 2006, the service caseload was approaching 70 service users in active therapy. In order to further increase the service caseload, a number of groups have been developed. These include Living Skills (DBT skills), Anger Management, Mindfulness, Motivational Enhancement Group for substance misuse, a Stages of Change Group, and a group to work on Interpersonal Relationships. The programme of group work shifts in this service according to recognition of need.

In line with the therapy model, service users in DBT who miss four sessions despite the efforts made to contact them are no longer in therapy, but can return of their own volition. 'We don't take self-referrals as initial referrals, but anyone who's left the service for reasons other than they weren't appropriate for the service, can just ring us up and reactivate treatment.' Until the recent waiting list arose, vacant therapy slots were maintained so that motivation could be harnessed immediately. This seems important in the context of working with substance misusers, as this client group has real incentives to cling to their drug of choice.

DDART utilises Trust services, and will, for example, refer to crisis and home treatment teams. All untoward incidents and threats are shared with the Trust, but the managers conclude that 'you sleep easier if you know that a client will ring you if there's a crisis'. In keeping with the DBT model, some service users are given out-of-hours telephone contacts, which they are permitted to use if they have not resorted to self-harming behaviour: the purpose of the contact is a brief telephone intervention reinforcing strategies to avoid such behaviour. 'You really are trying to make a difference here, not just patch up the mess afterwards …A call to the therapist is just one in a hierarchy of coping strategies.'

DDART offers carers assessments, individual sessions for carers, and a supporters (carers) group in order to increase the efficacy of the social systems around individuals to support their recovery. DDART offers limited family and couples interventions as needed.

1.5 Indirect service provision

The service managers have developed a five module training package for local service providers, and offer supervision of work in relation to this client group: uptake has been greatest in CMHTs, housing and voluntary sector drug & alcohol agencies. Consultation and supervision in respect of particular cases is also available, with or without the participation of the service user, and is built into the model of joint working around referred service users. In addition, DDART provides a review of all out of area placement requests for service users with PD to the local commissioners. Advice and treatment recommendations are given to ensure that all local area opportunities have been explored and tried. When PD service users are placed out of area DDART staff visit the service user and placement monthly to ensure consistent engagement and progress towards agreed goals of the placement. Liaison work with in-patients units is undertaken to facilitate the movement of PD service users out of hospital in a timely manner.

The team aims to work with other providers (and to advocate for those service users who are not engaged with other providers). 'This does relieve the burden of the Care Coordinator because we're doing a lot of pieces of work but they're keeping the overall eye on it, making sure it's all happening.' Staff said there was a tendency initially for other teams to make a referral to the service and then to withdraw support from the service user. 'During our assessment process many clients feel considerable stress and anxiety, and need extra support from services … and what we're doing is trying to promote thinking about the care of the client in a different way, instead of just dumping it on a poor CMHT worker who doesn't have the skills and so on and is overburdened. They seem happy with that because actually the majority of CMHT staff in our area don't see their role as therapeutic, they see their role as keeping an eye on the network around the client... we take on the actual care coordinating under the CPA roles very rarely, we resist it as hard as we can.' The team also offers training, but the impact of this is limited by high staff turnover in local public sector services: 'We trained 120 housing workers between September and October last year and 80% of them have gone.' Over time the training has had an increased impact on the wider health care systems.

1.6 User Involvement

There is a monthly service user forum to review the operation of the service, but it has been difficult to sustain interest among individual service users, who are more likely to attend one-off events. Service users participate in all new appointments as members of the interview panel. Service users also review and comment on documentation and policies, and participate in a steering group which oversees service developments. Service users are invited to participate in training events and conferences. Services users have reviewed and commented on current grant applications and it is hoped that DDART will employ service user researchers if the grants are funded. Service user feedback is requested (through questionnaires) at regular intervals throughout their involvement in the service.

2. Achievements and capacity of the service

153 referrals were received from November 2004 to June 2006, approximately 35% (the largest group) from CMHTs. At June 2006, 52 service users were being seen at least fortnightly, 37 receiving treatment (with the rest predominantly in assessment). Although 76 referrals were discharged, the reasons for discharge are varied, including failure to engage with treatment and unsuitability for service, as well as completion of agreed package of therapy. The biggest category of service users met criteria for borderline PD, with nearly 50% also meeting criteria for clinical depression, and alcohol the most commonly abused substance. At full capacity (with current staffing levels) the service expects to have around 12 service users in active assessment, 40 service users in treatment, and 15 in DBT. (At this level of activity, in June 2006, there were 20 service users awaiting assessment.)

By June 2006 DDART had delivered 30 days of training to services in the Waltham Forest area. The team was providing twice monthly supervision for staff outside the service to support the learning from the training package.

By June 2006 the roll out of DDART to Redbridge and local expansion in Waltham Forest was established (the IMPACT team), with plans to expand to the boroughs of Barking and Dagenham and Havering. As of February 2007 the roll out of DDART to Barking & Dagenham has been agreed, with two additional staff and one PD link worker to be funded by the PCT and the Tulip Trust. In addition the job description for a consultant psychiatrist in PD for Havering has been agreed and is with the Royal College of Psychiatrists.

This service is committed to using and generating evidence. The DBT-S programme is being used with a wider range of substance misusers than applied in the original evaluation in the USA (where subjects were all opiate-dependent and on methadone programmes

3. Departures from original specification: drivers & impediments

While this service has been set up to be consistent with the bid, DDART does not have social workers (2 FTEs were originally planned) on the team, and has had difficulty in retaining a sessional psychiatrist. There is lack of clarity around the role of psychiatry in a psychological therapies service. Two sessions were provided to the team by a senior consultant psychiatrist from June 2005-March 2006. The role included risk assessment, medical advice, diagnostic advice, and liaison with other psychiatric and medical colleagues. Psychiatric input is currently provided by a specialist registrar who is learning the DBT model. The psychiatric sessions will be filled in the near future with the development of a consultant post in PD who will have three session in the DDART (and IMPACT) service. Employment of Social Services staff (seconded), and finding social workers who want to take on the role of psychological therapists, are impediments. Links with the criminal justice system have been slow to develop. DDART has provided training for the probation services and works closely with probation on individual cases. However, plans to link more closely with court diversion, police, and magistrates courts has not been achieved to date. The service does not take on care coordination of service users: arguably to do so would compromise its ability to provide focused psychological therapies to a greater number of service users.

4. Findings from local audit and evaluation

By June 2006 5 service users were discharged from psychiatry back to the care of their GP (but with continued involvement of DDART), 5 had returned to work, one received a suspended prison sentence due to their involvement with DDART, and the number of admissions to in-patient units and the number of A&E visits had reduced in the cohort in treatment.

5. Areas for future development

This service (in common with many substance misuse treatment models) helps service users to decide whether they are ready to change, and invites them to return if they want to accomplish more at a later date. Future data should identify whether this takes place. The model offered by this service to individual service users is one in which staff and users collaborate to plan and implement intensive therapy: an important issue is how this fits into the service user's subsequent pathway or trajectory to 'recovery' (or whatever end-stage they aim for). Medium- to long-term outcomes for service users seen in the service would be very helpful to assess the impact of the model.

Although 15% of service users at June 2006 were of BME background, DDART feels that this proportion should be higher. Staff have the impression that is because people from an Afro-Caribbean background with PD and substance misuse problems may be more likely to be in contact with CJS services rather than health services. Following the merger with IMPACT, the employment of a Community Development Worker to explore the BME field is planned. A doctoral student in clinical psychology has commenced a project to consider the needs of the Asian population from the PD services.

In April 2005, the DDART senior manager (in collaboration with the Anna Freud Centre) received a grant from the Department for Education and Skills to evaluate the use of Mellow Parenting for mothers with BPD and their disturbed toddlers. This project, Better Bonds, may have the potential to address inter-generational 'transmission'. In addition, grant applications have been submitted to evaluate the introduction of family models of intervention for personality disorder.

Current plans have been developed for requesting funding for a split post with adolescent services and with older adult services to facilitate the current work of DDART with the older population and to encourage the adolescent services to consider different approaches to their work with emerging PD. DDART is exploring with learning disability services options for identifying and working with those with a putative Asperger's syndrome.

6. Summary of lessons learned by service providers

- Staff in this service need to be robust in the face of risk and anxiety, confident in using behavioural models of treatment, and willing to adapt to the model used by the service.

- Managers need to accept that there will be regular staff turnover as some staff find the service model and people with PD difficult to work with.

- Communication with the wider network of services is essential if services are to be supported by commissioners and managers. However, this reduces the capacity of clinical leads to see clients and supervise staff.

- The service experienced concerns around information sharing; comprehensive assessments gathered considerable information, not all of which is appropriate to share with the wider network.

- Considerable work has had to be undertaken to manage the anxieties of the wider system when working with a positive risk-taking model.

- Many difficult diagnostic questions have arisen around clients with comorbid BPD and ASPD, leading to some increased flexibility around working with people with ASPD.

- Capacity and waiting lists are important issues; tension between quality and quantity of input to individual clients and the need to see new clients is constant and difficult for staff and managers.

7. A Summary of Service Users' Views

A total of eleven people in contact with DDART (eight women and three men) participated in the research, six of whom were interviewed individually and five took part in a focus group. Interviewees had been in contact with the service for between three and 16 months and used a range of groups, DBT and individual therapy. Participants were informed of the research by staff and researchers using flyers and presentation to a service user group. Staff at the service selected and arranged interviews with volunteers according to the research sampling strategy.

Information and coming in

Most of the service users were referred to the service by a psychiatrist or psychologist and did not receive any information about DDART prior to attending for their first appointment. Many talked of their desperation for help; DDART was seen as their only chance for help and sometimes as the last resort. They described a wide range of difficulties in their lives, particularly in their relationships with others, and talked of not being able to understand or manage their emotions, as well as reporting such behaviours as self-harm, taking overdoses, abuse of alcohol and painkillers and aggression.

Assessment

Service users described the assessment process as lengthy and in-depth, involving many meetings and form filling over a period of several weeks. They found the process stressful as it raised many difficult and painful issues, and several people felt that more support should have been provided during this process. The service users generally appreciated the need for a thorough assessment process, however, and it gave a couple of people more confidence in the service.

For many people, this assessment process was the first time that they had been given a diagnosis of personality disorder. Whilst some did not like the diagnosis because of the stigma attached, others agreed with and accepted it. There were strong views amongst the former, with some feeling that the diagnosis was unacceptable and should not be used with younger people.

Support from the Service

All of the interviewees were receiving individual therapy and most were also taking part in one of the groups. Some felt that the individual therapy was helping them to understand themselves and their behaviour better. The telephone support was highly valued by most for the additional contact it provided with their therapist, but less so by the younger service users. There were mixed views about the Skills Group; a few people valued it for the skills learned that could be applied in their own lives, whilst others were not sure about its usefulness and a couple said they found it difficult to understand what was meant in the sessions.

Conditions and rules

Several people were uncomfortable with having to sign a contract to use the service, as they felt it was pressurising and unnecessary. Dissatisfaction was expressed both with the conditions imposed (e.g. if they miss four appointments in a row, they have to leave the service) and the limitations of the contract which specifies that service users have to stop certain behaviours before they can move on to talk about other issues. There was a view that this approach was inflexible, although it was acknowledged that some people had significantly reduced their self-harm as a result.

Relationships with staff

Most of the service users valued the relationships they had with their therapists. They felt their therapists understood them and treated them as individuals, and valued therapists for being non-judgemental, supportive and welcoming. The fact that the therapists were so positive and told them that they could change and have a better life was important to some service users. Some found the therapy process difficult and a few people said they found it humiliating or patronising, commenting on the lack of control or choice they felt they had.

Involvement

The DDART service user forum, which is organised by staff, seemed to be struggling to establish itself. Most of the interviewees knew about the forum, although only a couple had attended. It was thought to be poorly attended and predominantly for information giving. Although most service users felt consulted in decisions about their own care, some felt that ultimately it was the therapists who had the power in the relationship. (One person referred to the conditions of attending therapy in this context).

Outcomes

A number of service users described significant positive changes in their lives as a result of their involvement with DDART. Several people felt they had gained a greater understanding of themselves, their behaviours and their emotions. Some said that their relationships had improved: that they could communicate more effectively, were more assertive, understood others more, and generally had healthier interactions with other people. Changes in feelings were also described, such as being calmer, less stressed, more positive, having fewer extremes of emotion, being less angry and more tolerant. A couple of people said that their self-harm had reduced significantly, and one that their substance misuse had reduced. Reasons given for changes were the hope instilled by the therapists, being seen as an individual and being listened to. Learning new skills and finding out about the dangers of alcohol and drug abuse from the therapist were also seen as important components of the therapy.

Many also felt that therapy caused a range of difficult emotions to be stirred up, and a couple of the younger service users did not feel that the service was helping them at all. In general, the benefits were appreciated more by those who had been using the service for longer; a few who were nearer the beginning of their journey were hopeful that DDART would be able to help them.

Suggestions for improvement

The service users made a number of suggestions for how the service could be improved. These included the provision of support workers, input from a social worker, more support during the assessment process, more local services, the provision of relaxation and alternative therapies, more peer support, changes to the contract and a dedicated service for young people.

A3 Service User Network (SUN)

1. Description of Service

1.1 Aims of pilot service (from bid)

▪ To develop a Service User Network [SUN Project] for people with PD which satisfies both national and local agendas;

▪ To support, train, and empower key service-users themselves to be an integral part of the SUN Project;

▪ To enable individuals who do not successfully access existing services improve and manage the difficulties associated with having a PD.

▪ To provide an inclusive service for people with diverse needs specifically including, black and minority ethnic groups, and individuals experiencing a variety of difficulties in addition to their PD, eg substance-misuse.

1.2 Staffing the service

The project is funded to employ 3 personality disorder liaison workers (PDLWs), plus a senior supervisory clinician / team manager. Most staff are qualified in psychology, medicine, mental health nursing or social work. Their remit is to outreach for the service, facilitate groups (including arranging for visitors and advisors requested by users), facilitate access to other services, and support and train Lead Service Users (LSUs) who may eventually take on group facilitation. The team has 0.5 WTE of a Consultant Psychiatrist in Psychotherapy, who has been vital to the service design, staff training and supervision, plus part-time administrative support. The project initially employed a project manager for set-up arrangements (including policy liaison with service users; publicity; finding premises; working with Trust on legal relationships). As in other pilots, the innovative aspect of the work could not be genuinely reflected in the job description, and much of the first year was spent in training. 'What was advertised isn't what we were doing … There was a lot of confusion, doubt, whether we can handle that … but you know the end product is really great... a lot more skills have been developed and learnt … Some members of staff absolutely love their work: some didn't find it so great and would prefer to be more sort of therapeutic and left.'

The service has funding for 2 lead service users (LSUs), to be recruited from service users (known hereafter as 'members'). The training and development of LSUs was primarily motivated by the desire to have a self-enabling network: it also has the capacity to expand resources, for example by permitting the service to offer user-led evening and weekend groups. Given the need for members and the service to gain confidence, it has taken almost two years to begin training for these posts. Although initially envisaged as paid posts, there was some anxiety from members about the impact on benefits, especially if an LSU became unwell; the sufficiency of training, and the possible impact of introducing hierarchy between members. By Summer 2006, a bank system was in operation, with which self-selected members could register for training: individuals would then be appointed as LSUs. The bank permits an LSU to "step down" from the role if they chose to do so or becomes unwell, while preserving a pool of potential substitutes. The posts are recognised by South West London & St Georges Mental Health Trust's groundbreaking User Employment Programme, which provides support to service users in seeking or maintaining employment within the Trust. LSUs are recruited from all four Borough-based services, as their key function is to facilitate groups.

1.3 Client group and referral process

The route of entry to the SUN is by self-referral only, and referrals from healthcare professionals are not accepted. The SUN is explicitly aimed at people with PD though service users are not formally assessed and may not have been given this diagnosis. .The professional team provides assistance to prospective members in deciding whether the service is appropriate for them, but 'If you think you need to come that's good enough for us. It's your life. We respect your opinion that you want to come.' The key criterion is that a prospective member has the capacity and willingness to complete a Crisis Plan. Members are also encouraged to complete a Personal Development Plan, which is a more positively-focused document and process in that it explores the member's aspirations that the SUN will aim to facilitate. After some initial reflection, it was decided that service users should be resident in Borough, in order to facilitate support during crises. A key principle of the service is that people are not assessed, although the crisis plan requirement acts as a self-appraisal of a person's difficulties, and the resources they have to deal with it. New members work with other group members to review crisis plans, which may then be modified and improved, taking into account the group's experience and joint resources. Self-referral is designed to include people with no prior or current contact with statutory MH services. Members choose to attend meetings: those who do not attend for 4 consecutive weeks are deemed inactive members, but can restart attendance at any time, although they are asked to call the service first. One advantage of this open-door policy is that people can take breaks if the strain of participation becomes too great.

1.4 Model of intervention, expected outputs and outcomes

The service has an office base within Springfield Hospital, and is hosted within South West London & St Georges Mental Health Trust (SWLSG). Four locations were planned for the groups, and establishment was staggered (between May 2005 and January 2006) in the following order: Wandsworth; Richmond and Twickenham (the initial commissioners for PD services within SWLSG catchment); Merton and Sutton; and lastly Kingston. If demand is there, groups operate for 3 hours per day on weekdays. In common with some other pilots staff have found the provision of services away from the service base has stretched staff capacity, and the running of uninterrupted services has been challenging with little 'slack' for holidays and sickness.

The service design has three components: (a) the daily service (the groups and liaison activity), (b) the out of hours peer support service (OOHPS) and (c) evening and weekend groups, in which members arrange to meet without facilitation by SUN staff. Each daily group comprises a three hour session. The structure of the group is very specific and boundaried. The group starts with the facilitator offering those present the plan for the meeting (so there is security); the record of the last group is read; there is 'check-in' in which members have the opportunity to appraise how they are; there are set breaks and the subject of the day's group is clearly stated. The group concludes with appraisal of the impact of the group on those present, and plans are made to cope until the next meeting. The main part of the session is a one hour slot allocated to a group topic, broadly welfare, psycho-supportive or concerning social contact/activities. As the groups become more established they can evolve to cover any subject decided by the group: so far, there has been significant support for practical as well as emotional subject areas, e.g. exploring an individual's practical difficulties, and highlighting a benefits service within the Trust. Members often have expertise and experience they can share with others in the group, but may find those groups intended to be relaxing among the most challenging: 'It's difficult to play Frisbee with someone you have had a run-in with rather than going off and cutting yourself'.

Attendance of a group was set at 20-25 maximum, but because of the fluidity of attendance – and the fact that there are no penalties attached to non-attendance - it can be difficult to predict numbers. Members report (to staff) that the lack of compulsion is itself empowering. There is a culture of phoning in to apologise for absences: and people feel missed, cared about, and learn more about the impact they have on others. Those who miss four consecutive meetings are contacted by the group through a personal letter composed by the group: if there is no response, the individual concerned becomes an inactive member and may need to complete a new crisis plan if s/he returns. As with therapeutic communities, the members attach to the group, and staff do not permit themselves to become confidantes of members: all 'confidences' are fed back to the group. 'People know from the start that this is the way it is going to be and some like it, some don't but they know it is just the way that the groups work.' Secrets are believed to be damaging. Members agree what is recorded in the group's logbook, as explicit detail may be unnecessary. Staff facilitate but do not lead the group or assume superior wisdom. Regular clinical supervision utilising role play are used to explore situations in which staff have felt uncertain about their facilitation.

Considerable time has been invested in devising and agreeing with service users the operational aspects of the service model, including the development of the crisis plan, and the out-of-hours peer support service (OOHPS). This is run by trained service users (two per session for mutual support) with mobile phones and access to crisis plans. Protocols have been developed to manage individual calls according to the crisis plan for the individual, which may entail prompting to contact mainstream services. Calls are time limited (according to the local group's prescription). The service is designed primarily to avert crises by supporting the person in crisis to activate the crisis plan made, and this may be revised after the incident. Staff state that protocols offer a safer alternative to unsupervised contact because they help trained users respond to crises more strategically and provide a framework and boundaries that guides the interventions they provide.

Although the SUN had some training and support from Henderson Hospital, Winterbourne House and their members, they do not consider themselves a TC (because irregular engagement and attendance is permitted, and the service will eventually move toward peer, not staff-held, group work). The service has also resisted description as 'therapy'. 'If you call it 'therapy' there's an expectation that people will get 'therapied.' There's an expectation that 'well we're doing therapy with the aim of "x."' No longer will you feel this way or do this thing, and you move on. Most services have an end point .. (That) has been used in order to exclude people … What our service users tell us, one of the things they really like about us, is there's no time limit.' It is accepted that the service may have 'therapeutic side effects'. Another staff member suggests that the group is increasingly self-reliant, with the facilitator acting as an occasional 'guide' and mediator: 'What we bring is the soft edge to some of the communication and that search for communication that I think members have.' The ethos of the service is to equip members 'to learn how to support each other and support themselves'. Another adds: 'If there's something that's very unhelpful going on, the staff will say … "Hang on, can I ask the group. Is this … is it helpful? … Our aim is definitely to be supportive. Now that doesn't mean to say we don't say difficult things but we make sure we do it supportively.' PDLWs facilitate the process through which members arrive at and implement their own strategies and solutions, and as far as is consistent with the management of risk and practicalities, do not take on tasks themselves. It is a source of satisfaction to staff that members own and implement much of the activity and processing of the group, including the implementation of the risk protocol. Staff reign in their urge to offer professional 'insight', and choose their words carefully if they do intervene: 'it's much more helpful to use the skills in the group in the long run because that's what makes it experience, empowering.' The logical extension of this philosophy is to train service users to take over from staff, and this is the rationale of the Lead Service User role.

The SUN model of communication within groups, refined and carried by the staff, is thoughtful and structured. The theoretical underpinnings of this model of working are based in Coping Process Theory and the concept of appraisal modification is a key element in its effectiveness. Staff and users alike appraise and re-appraise their difficulties, and particularly the available resources and strategies for managing them. When difficult situations are discussed, the facilitators try to draw out not the origins of the problems, so much as the means of coping. The group interaction enables participants to re-appraise how they come across to others, both within the group and elsewhere. Openness, consistency and clarity are key values for staff and members, and there are protocols to deal with risk, harm to self and others and statutory obligations. The limits of the service are clearly articulated.

'The greatest revelation for me is the fact that I don't have to have all the answers myself or I don't have to go off and find them: and yet they can still be found, not necessarily that day or that hour, but something will come up.' The theory and the model develop most in difficult and testing situations.

The SUN has had to work hard to carve out a distinct identity within Trust procedures and governance. Members' records are not shared with the Trust, and crises are increasingly, as the Out of Hours Peer Support Service (OOHPS) develops, facilitated by contact with other service users: however, SUN membership has no direct impact on the use of other services, and members may gain some knowledge of them through membership. The clinician in the team does not act as RMO, the service does not operate the CPA, and enquiries from other health professionals are fed back to the person concerned within the group so that they can discuss what, if anything, is shared, or, in the case of Child Protection, how the information will be shared. It has taken a year to overcome obstacles to the establishment of the Out of Hours Peer Support Service (during which members were thought to have phoned each other without benefit of protocols) because of legitimate concern within the Trust that the service would be used by those in crisis and therefore at risk. In the event, after 10 months, independent legal advisers suggested that the service's legal duty of care was different from that of the Trust generally: members retained responsibility for engaging with the OOHPS service, or for calling an ambulance or other assistance, and for other actions assumed to be risky, and that this should be stated on the crisis plans.

1.5 Indirect Service Provision

SUN staff have publicised the service with local staff teams to increase awareness, but it remains the case that people must self-refer to the service. Once the full complement of groups were happening, there was little capacity left for staff activities outside the group work, although staff may develop links with local services – eg Samaritans - to facilitate group aims, such as to provide a suitable option for crisis mediation. SUN staff say they have felt that general MH Trust staff were supportive, if only because of the paucity of services for these service users, although there was some confusion around the SUN's desire to target people not in current receipt of services. Members have participated in negotiations with the Trust, and have shown both pride in the service and diplomacy, and it is likely to be members who will increasingly take on the function of publicising the model, and using presentations to improve local services. For example, one of the local crisis lines was rated as poor by service users, who (Summer 2006) were planning to take up the invitation to demonstrate a new way of working to them. Members have the potential to take the lead on the 'spoke' and training aspects of this user-led pilot.

1.6 User Involvement

A key aspect of the service has been the involvement of members in developing the organisational and operational framework, publicity material and policies, and the crisis plan and protocol for OOHPS. Initially, users of services were contacted via CMHTs: 10 consultation meetings were arranged through these contacts, generating a core group of 6-8 users who have been involved in developing the service from the beginning, with some of these members supporting development in the later groups when the demands on the service permitted less investment in consultation. User involvement in policymaking has reduced ambiguity, as described in relation to the risk protocol: 'Say you call an ambulance, it needs to be made explicit as to who's going to go in the ambulance with somebody. To begin with the group expected that it should be the liaison workers that went and the liaison workers expected that it should be the group… those sorts of things were sorted out.' Negotiation with users was time-consuming, and the lengthy process has derailed the timetable for setting up the groups. Some staff suggested that fending off user cynicism had been wearing: users could not trust that this unprecedented service would be delivered. However, evidence from participation at learning networks suggests that there is a high degree of user ownership of and satisfaction with the service. Some staff see the future as their own redundancy, while for others, clinicians should work for the client group. SUN managers report to a steering group including both Trust officers and two SUN members.

The employment of members as Lead Service Users has been slow to develop, even within a Trust renowned for service user employment. Development was hampered by the need to advertise PD as a criterion for employment; the difficulty in working out a payment policy which did not jeopardise benefits, especially if the person suddenly became too ill to work; and the Trust's insistence on applying CRB checks and investigating sickness records and occupational health profiles. Potential applicants were seemingly less concerned about payment, seeing the training and experience as valuable; but were concerned about the potential for competition or hierarchy dividing members, and the possibility that responsibility might precipitate stress and decline. One staff member reported a member saying: 'I've spent last 20 years criticising clinicians, I don't want to be one.' The training of a 'bank' of staff who can fill the role of LSU has been adopted as one way of disseminating responsibility and mitigating both status differentials and stress: the training was beginning during our last visit in Summer 2006.

2. Achievements and capacity of the service

SUN have fulfilled their aims to establish services in four Boroughs. The bid aimed to recruit and retain around 20 service users in each group: as at October 2005, the Network had met this objective in all but one of the four groups. Data provided by the service indicates that between April 2005 and September 2006 the SUN Project had 198 prospective members, of whom at least 171 had attended at least one group (range 0-126 attendances, median=5). In order to publicise the service, SUN have distributed over 9,000 leaflets to local service providers. The leaflets were largely designed by members of the service.

The service has the potential to offer guidance and support in all areas of life, including the practical. As this is generated from within the peer group, it is not predicated on specialist knowledge, and so may amount to new skills and capabilities. Although staff support is thinly spread, the service model is innovative and may have wide ramifications. The service has also successfully clarified the legal status of its duty of care to members, and paved the way for other services to establish user networks with Trust support that operate under different provisions. The model of provision appears to be sustainable, replicable and cheap.

3. Departures from original specification: drivers & impediments

The service has been slow to develop, although this appears to be consequent on its dependence on service user input into design, policies, etc. The training and development of the Lead Service User posts (see above) has been held over until the establishment of the four key services and the specification and piloting of OOHPS; this has then delayed the potential for the evening and weekend groups to happen. The change of senior management at Trust level, and the need to seek legal clarification over the risk and governance aspects of the project (particularly the user-led out-of-hours support), have also delayed progress. Another key factor in the slow start-up is the innovative nature of the project: all staff had to be trained and there was some early staff turnover because not all those engaged wanted to work with it. Finding suitable premises was also challenging, and the voluntary sector has been the key source.

The pilot service across the five PCT areas (the areas covered by SWLSG, the host Trust) was commissioned by Richmond & Twickenham. With the advent of PCT funding, the service may soon need to contract with five boroughs. The service does not have a SLA, but has the capacity to be placed within developing PD services in all five boroughs, possibly at the bottom of stepped care.

4. Findings from local audit and evaluation

The service carried out an evaluation with all members who had attended at least once. The members were sent a patient survey to complete comparing their experience in the 6 months before joining the SUN and the 6 months after. Results showed that more than half of the service users agreed or strongly agreed with items rating improvement in wellbeing (such as less exclusion, more support, more empowerment etc). They also reported a reduction in unhelpful service use. This included a 30% reduction in A&E attendance, 38% reduction in unplanned (emergency) CMHT appointments and a reduced number of bed days in hospital (both planned and unplanned). Cost savings for the reduction in CMHT appointments was estimated at £2,635 and for reduction in bed days at £44,125. Service users also reported having better access to the services they did need (with a 100% increase in the numbers rating access to services as quite or very successful).

5. Areas for future development

The role of the SUN in relation to its external partners is likely to expand now that it is fully operational. The groups are co-terminus with 4 PCTs, and the service therefore has an interest in engaging more closely with the distinct PD services operating in the different areas. It is commissioned by Richmond, who have expressed interest in the service acting as a first call in a stepped model of care within a new PD service pathway. The service is now managed by Sutton, and may develop closer links with Henderson Hospital. Members of the Kingston group have ambitions to align themselves more closely with their local provider Trust, to legitimise user-led services and outreach more potential members. The service also has good relations with voluntary sector agencies (from whose premises they operate), and there is interest in disseminating the model more widely through research.

The team plans to develop more BME contacts, possibly with carers and families. SUN has found that a group attended by 15 or more is probably too large to address individual needs, so development of the service and its resources will need to follow demand.

The key project for SUN at the point we last saw them was the development of Service User Leads, so that the service can operate as a fully self-sufficient network for members. This should pave the way for extending groups to weekends if there is demand, as this development was conceived as independent of staff cover.

7. Summary of lessons learned by service providers

- People with PD are able participate in designing and providing support groups.

- The success of such groups may depend on their being underpinned by a coherent theoretical model which is simple to understand and easy to teach to staff and service users alike.

- The involvement of peers in the assessment of people with PD may yield information that is more accurate; shame and other barriers to disclosure may be reduced.

- Arrangements for providing support and access to services for service users who take on lead roles need to be carefully considered.

- Groups need ongoing supervision if they are to be sustained.

8. A Summary of Service Users' Views

Twelve people linked to the SUN in South West London were interviewed: ten in individual interviews (four men and six women) and eight in a focus group (four men and four women). Six of the people involved in the focus group had also been interviewed individually. Interviewees had been in contact with the service for between one and 18 months and were associated with four different geographical areas in which the SUN network has been established: Richmond and Twickenham, Kingston, Merton and Sutton and Wandsworth. Many of those interviewed had used all parts of the service. Participants volunteered for the research in response to flyers and group meetings. Service user researchers then arranged interviews with them directly.

Coming in

Most service users mentioned the ease of access into the SUN project; it had been possible for some people to ring up and get into a group within a week. The opportunity to self-refer and not to have a risk assessment was valued, and seen as empowering. Most people's introduction to the project had been to write their crisis plan with the support of the group. This was seen by most as a good introduction to the group, helpful and supportive, although one or two people felt that it was undertaken too soon or too immediately on contact with the project, or had caused some distress. A few people enthused about finding a place where they felt accepted or about their first impressions prompted by the name 'service user network' or the potential Lead Service User role.

Diagnosis

Mixed feelings and experiences were discussed about the diagnosis of personality disorder. Since the project is advertised as being for people with personality disorder, they were in no doubt about the purpose of the project. For a couple of people the diagnosis was seen as positive; one person felt that it gave him an identity. One person had originally been angry, but had come to accept it and now feels that PD should be taken more seriously. A few people chose to accept it for practical reasons within the context of the project.

Support offered

Peer support is at the heart of the SUN Project; groups meet several times a week with staff liaison workers to facilitate. Different groups were mentioned in the interviews: several people particularly valued the emotional support groups and a few highlighted the social group. A couple of people said that the support improves and becomes more meaningful as you get to know people better. A couple of people felt they were giving too much and receiving too little support, and a couple said they would like the opportunity to have individual psychotherapy alongside attending the project groups. There was also a suggestion that this project could not provide everything that a person might need. One or two people said that mainstream services believed the project to be an alternative to the support of a CMHT; they were clear that this was not realistic. Many people expressed concerns about the delays to the promised Lead Service User Role and the out of hours peer support line. Concerns focused on the support required to fulfil these roles, the need to be in a good place yourself, the possible pressure on people and the support therefore needed – one person said that although self-empowerment is very important, it needs underpinning with professional support. However, people did feel the need for out of hours support and many were highly critical of the NHS Trust's crisis line.

Group Process

The ethos of the SUN project is based on group process; individual contact or relationships with staff members are discouraged. Service users can make contact with staff in between groups by phone or text but they are encouraged to bring everything back to the group for it to be discussed and dealt with there. On the whole, people were positive about this and encouraged others to bring things to the group. Some talked of the sense of belonging and commitment to the group, of all being equal and held within the group.

Relationships with staff

Service users were very positive about the staff, describing them as easy-going, genuine, kind, caring, professional, supportive, understanding, gentle but skilled, non-judgemental and compassionate. As one person said 'they are there for us if we need them'. One member of staff was reported to be patronising and abrupt.

Peer support

Peer support is central to this project, and service users are actively encouraged to keep in touch outside the groups. Several service users emphasised the value of the service being PD specific; it gives a 'common denominator' to the groups and enables people to understand each other better. People talked about the value of sharing similar experiences, supporting each other, and making friends. They said there is a mutual understanding between group members, and for many people it was clear that the relationships with other group members was the most important aspect of the project. Most people talked of making friendships through the groups; they would regularly meet outside the groups, and support each other through a crisis. One or two expressed reservations about the existence of 'cliques' and the potential to feel left out at times.

Involvement

Most people felt very involved in the project and its direction as well as in their own care through the development of crisis plans. Several had attended seminars and conferences, sometimes giving presentations. People talked of having a big say in the project, of being committed, even dedicated, to the project. This was a vital part of the project to many people. However, a few people expressed concern about the length of the initial consultation period; it had lasted several months, and some people had dropped out. Although they had felt fully involved and consulted, they were frustrated with the lack of progress. Several people had been interested in, or applied for, the Lead Service User role, and were frustrated by the delays to this as well. At the time of the interviews, the project manager's post had just been terminated without people knowing it was about to happen. This had led to concerns about 'behind the scenes' politics and potential funding problems. Nevertheless, they had been able to voice these concerns and reported that liaison workers were trying to find out further information.

Outcomes / Changes

Most people reported positive changes in themselves as a result of their involvement in the SUN project. People mentioned feeling more self-aware, having more confidence, gaining hope and ways of coping, feeling stronger or feeling good about themselves. Seeing other people getting better and overcoming obstacles was a source of hope. Several people said they had learnt a lot about interacting with people, communication and relationships. One person said he had a social network he had never had before; another described the project as 'life-saving'. A few people said that they were taking fewer overdoses and making less use of A&E, having fewer crises or handling them better. A couple of people felt that having a say or being heard was a major part of the positive impact of the project, and for others it was the peer support that had made the difference. Several people said they felt that they had more to do, more progress to make, and a couple felt that individual therapy would help with that.

Ideas for improvement

For a couple of people, no improvement was necessary, other than to expand the model into other London boroughs. Others, though, could see space for improvements. They mentioned a range of factors associated with the groups: more frequent groups, or the size, structure or timing of groups. Several people mentioned the need for some or better crisis/out of hours support, or access to staff in the evenings. A few people said they would like some therapy for themselves or CBT-type input into groups. Despite some concerns for the future, a couple of people said that they could see the project broadening and developing, so they were confident that change would happen.

A4 Cambridge and Peterborough Service

1. Description of Services

This service has two distinct aspects: the Cambridge Complex Cases Service, a direct therapy service to service users based in Cambridge, and the Peterborough consultancy service. As the services cover different geographical areas, and have taken a different approach to working with people with PD we have provided separate descriptions of the services they provide.

1.1 Aims of pilot service (from bid)

- To provide access to specialist services for people with personality disorder.

- To establish a 'hub-and-spoke' model that delivers a network of services and expertise across agencies.

- To provide training, supervision and support in working with people with personality disorder to staff within and across agencies

- To establish user and carer support networks.

- To work with service users and carers to ensure that services are responsive to their priorities.

- To evaluate these developments and adjust service models in the light of experience.

The core functions of the teams will be to:

- take on service users for assessment and treatment in line with the principles of CPA.

- provide consultation, support, supervision and training within adult mental health services across the Trust (CAMH, A&E, substance misuse) and with external agencies (SSD, Probation, Housing, Primary Care)

- develop self-help, user networks

- set up 'out-of-hours'/crisis arrangements linked to the Trust's developing crisis services.

The pilot service is divided into two distinct parts: the Cambridge Complex Cases Service (based at Addenbrooke's Hospital in Cambridge) and the Peterborough Personality Disorder Service, now based at Peterborough & District Hospital. (Cambridge & Peterborough, as distinct locations, are used below as abbreviated signposts to each of these services.)

1.2 Staffing the service

Cambridge Complex Cases Service (CCCS):

CCCS is a multidisciplinary team led by a Consultant Psychotherapist, comprising a consultant Psychiatrist in Psychotherapy (10 sessions); Senior Adult Psychotherapist (10 sessions); Senior Clinical Psychologist (10 sessions); 3 Psychotherapists (26 sessions); Probation officer/Psychotherapist (10 sessions); Social worker/Psychotherapist (8 sessions); Occupational Therapist (6 sessions); Music Therapist (1 session); Assistant Psychologist (5 sessions) and half-time admin support. The service also hosts SHOs, specialist registrars and psychotherapists for secondment from time to time. Staff roles are flexible: psychotherapists expect to case manage and care coordinate service users, involving care planning across different agencies and in relation to practical as well as therapy matters. Team members have roles suited to training and background – OT, group therapy, etc – but also take on responsibility for particular types of counseling & support (eg marital, children and families) or other team functions (eg research and evaluation).

Supervision and a supportive working context, which frees the staff member from institutional anxieties as much as possible, are crucial. The style of leadership is such that there is no ambivalence around risk: the lead clinician takes responsibility for adverse events. 'And we think of that as a way of dividing anxiety within the team, so that it's not too heavy to pick up.' In addition, 'We have feedback everyday after the open clinic, and it's usually feedback from the open clinic but anything from the night before, or over the previous weekend … we expect to share whatever contacts we've had with the rest of the team. And we need to do that. And it took me a little bit of time to get used to this kind of sharing, because as a doctor obviously you come from a different place I suppose. But it's been really helpful, and I think it's absolutely the way to do things… On Tuesday morning we have a clinical meeting: there's an agenda and we talk about individual patients and the groups. We review the groups and … we think about any children at risk, children of clients. And we think about the waiting list, if there's anyone on it and new patients.'

Peterborough Personality Disorder Service:

The money for the Peterborough service was for staffing only: a fulltime Consultant Clinical Psychologist or Adult Psychotherapist & group analyst, half time Consultant Psychiatrist and Psychotherapist, a fulltime development worker, since become Adult Psychotherapist and PD Service Liaison Officer (0.8 from July 2006), halftime Assistant Psychologist and part-time administrator.

1.3 Client group and referral process

Cambridge

CCCS caters for adult service users (25+) in the highest range of severity. The vast majority of service users have had repeated hospital admissions and suffer from an average of 5 (SCID II rated) Personality Disorders. The service covers a large geographical area: Cambridge and the surrounding countryside, covering 3 PCTs and up to 300,000 people. Surprisingly, most referrals are not on enhanced CPA and will be registered and care coordinated either within the service or in collaboration with the service. 'The vast majority of them have 4 or 5 Personality Disorders. We try to take patients who have multiple involvements with the rest of the healthcare network or who have heavy involvement with forensic and/or children and family services.' They also tend to 'mop up' those that don't meet criteria for, or are excluded from, other services, e.g. the Eating Disorders service, and those under 25 with forensic backgrounds (who are excluded from youth services). It is felt that care coordination should stay with the CMHT if there is good attachment, as this enlarges the service user's support network and the capacity of the team.

There are no blanket exclusions, although the head of service will see all service users to assess risk. Severe substance misuse, use of violence and/or lack of motivation to engage would disqualify a person from this service; and the service also seeks to complement, not disrupt, existing networks. 'Our patients are almost invariably locked into huge quantities of very different health care and we want everyone to agree that a referral would be a good idea. The caring network around the individual agrees that the referral should take place….That is our criterion.' In addition, 'There are people we have taken on and have not got very far with. You have got to have some glimmer of a working alliance, the person has got to want to have, expressed some degree of wanting to be helped.' Most early referrals were of women, but links with forensic services appear to have fostered increasing referrals of men. The team includes an ex-probation officer, who acts as a linkworker and has brought in Multi-agency public protection arrangement cases (MAPPA), people on Drug Treatment and Testing Orders (DTTOs) and other people with offending histories. The linkworker has negotiated some confidentiality barriers with the CJS in order to develop relationships with these service users. The linkworker has options to bring them into the service, to dispense therapy herself, or work with the Probation Officer. Some encouraging reductions in offending – and in custodial sentences – were reported: service users may be poorly motivated to engage with health services, but 'most people … at the best don't want to end up in jail again'.

Peterborough

The Peterborough area has a population of around 220,000 people. 'Referrals' are of a different character, and may be of teams or single professionals who want consultation, supervision and training, mostly around named service users. Services engaged with are those that deal with service users of adult mental health services in Greater Peterborough. The service does not deal with services for those with forensic backgrounds, learning difficulties, or young people.

1.4 Model of intervention, expected outputs and outcomes

Cambridge

The Cambridge Complex Cases Service (CCCS) in Cambridge was built upon an existing smaller service nested in the Psychotherapy Department at Addenbrooke's Hospital, and takes most referrals from psychiatric hospital and community services (plus a few from GPs). The service aims to provide therapies that will lessen the impact of PD on the service user, and on (professional and other) carers. If the service user agrees to work with the CCCS, they are allocated a case manager from the team who will begin to assess their needs against the therapies available. The range of available options include individual psychotherapy or CAT (cognitive analytical therapy), group therapy (including music therapy), social work, and work with the forensic link worker. The Cambridge service also has access to a separate psychological therapies service to which it can refer. 'I suppose the kind of, the overall rationale of our therapy is that we are not in the business of trying to cure anybody, but we are trying to help people manage better, manage a bit more creatively or manage a bit more positively or a bit less dangerously.'

Service users are assessed for risk and need, a treatment offer formulated and discussed. Some will get individual therapy once or twice weekly (based on CAT), and small group therapy (with 4-8 service users) which would be once or twice weekly. In addition to two therapy groups (see below), there is a men's group, a music therapy group, a 'bodies & minds' group (set up in response to body dysmorphia and self-loathing among service users) and a mother's group which has a crèche. (The crèche facility is run in a social service's family centre with attached crèche.) A group known as Life Works is open to all who are or have been service clients as a rolling programme of psycho-education with a social element. There are also a number of groups open to members of staff as well as service users, to attend. There is a Mindfulness group, which is based on mindfulness and meditation, and a book club which also critiques films. Occupational therapy and social work interventions are also available to individual service users.

'We run groups and the groups are where the body of our patients are treated really. But there's no doubt in my mind that we very actively work towards stimulating people to attach to us because it's felt that… avoiding that or not enabling people to attach is going to mean you're going to significantly impair their capacity to improve…. I can't see how a vague attachment to a body or a model or a group of clinicians is going to be as supportive as an attachment to a person in the service. '

The unifying element to all treatment is the team's collaborative understanding, based on the principle of compassionate observation, of the difficulties that face the service user. Frequent case-based discussions ensure a unity of approach. Two therapists enlarge on the advantages of CAT. 'The key thing about CAT is that it tries to steer away from the more classical psychoanalytic model where the therapist, the analyst is certainly the one in the driving seat interpreting the patient in a world whether they like it or not and often leaving them totally mystified… It often helps to have a visual model, principally because it's something that they can take away and revise, look at and think about…. often people with PD have very, very narrow, very limited capacities to think outside of the margins of their own experience… One of the main things that we concentrate on (is the) drawing of an SDR (Sequential Diagrammatic Representation), drawing a diagram which conveys the central reciprocal roles that the persons' involved in … But if you haven't established a working alliance of any kind, then it doesn't matter how accurate your SDR is: its not going to help very much.' The diagram can communicate to other stakeholders how the service user responds to the world, 'the dynamics of their relationships: with the patient's consent it is possible to send that to somebody else from another service … I think with that kind of reasoning a lot of people think 'okay this isn't quite so bizarre or as bad as it seems' The model can also incorporate aspects of DBT: using group work and individual therapy; having service users work with more than one member of staff; mindfulness as a technique to accept and tolerate emotion.

Care plans and targets are negotiated with the service user, with reviews at least every six months. Some staff feel that practical support is underplayed in the service, although links have been made with CAB, housing services, etc. Service users' lives and needs can be very complicated. An account was given of one service user's (own and family's) personal health and social problems. 'It's all very well to say, 'oh come here and we'll help you think about your problems,' and not knowing that actually you go back into a situation 24/7 where… your sort of diagram is so powerfully maintained by that context you go back into. Also we're beginning to find out more things that aren't in the literature… more people with obsessive compulsive disorders, people who are in that place where a number of diagnoses probably overlap, like schizophrenia and mood disorder and autistic spectrum disorders…'

Treatment may be assertive or reactive: it has been found that people require different levels and intensity of support at different times. The service user also has access to an 'Open Clinic', which operates every weekday morning 9-10am, and where the guarantee is that the service user will be seen or spoken to (if they telephone) by a member of the team. Service users can call or attend at other times and every effort is made to accommodate them, but the Open Clinic offers guaranteed input. Service users can also telephone to speak to a member of staff two nights a week between 7.00pm and 10.00pm. Both the Open Clinic and the Evening (telephone) Clinic are well used: 'People make wise use of them … they're not completely inundated, and I think some of that is about people knowing it's there.' Service users also use e-mail extensively 'because they know they're going to be read. And also it stops … they'll use that to stop themselves self harming.' The Complex Cases website has a chat room forum that was set up by the service users. There are no barriers to informal contact between group members, and this may develop of its own accord.

Any service user who self harms is urgently booked-in to see the head of service. The emphasis of these meetings is on encouraging the service user to think about the state of mind they got into that felt to them as though self-harm was the only way to deal with things. 'We recognise that one of the things that therapy can do is, particularly with people who have attachment difficulties, is that their level of anxiety becomes so intense that self harming becomes a way of managing that…. And that would be explained to the patient as sort of needing time out for a bit. They wouldn't be dropped from the service, they would in most cases go to Life Works, they might see their case manager every fortnight but they wouldn't have intensive therapy until it was felt that they could cope with it again.'

It is difficult to hold people in groups, and attendance can be disrupted by events outside the facilitators' control. Group work is seen as important, though staff report that service users may prefer one-to -one work: 'you suddenly get the leverage that comes from the fact that patients can't discount each other's experiences in the same way that they can discount the experiences of paid professionals.' Early experience of group work was that they were dominated by women, many self-harming, with eating disorders or agoraphobia. Facilitators also found participants appeared clinically depressed, unresponsive, and unable to tolerate more than relatively superficial probing. A subsequent group is more articulate, only episodically depressed, and more able to talk about emotion and tolerate the anxiety generated without resorting to self-harming. Both groups run for 90 minutes twice weekly. 'The advantage of having these groups which we call Slow Open Groups, is that you have the very experienced members, and the new members and the very experienced may have been in for a couple of years, the new ones come along and they can share their experiences with them, how difficult it is coming in to a group.' There is a strong onus on attending the groups, as they are small, and one group is experimenting with examining the group's behaviour using CAT techniques. At the other end of the scale, the Life Skills Group is an inclusive activity, rather than therapy, group. It takes place away from the clinical environment one afternoon a week, and has involved cooking, outings, games and other opportunities for socialisation. It can also be used for holding service users who cannot currently receive direct therapy.

The CCCS has developed a number of leaflets to inform staff and service users of other services about PD. This serves to supplement the formal training offered by the team: sometimes (as in Probation, which is already overloaded by training in the new provisions around the National Offender Management Service) very few staff can attend training, and the leaflets act as a starting point to facilitate contact.

The probation link worker holds a caseload of service users within the Probation Service and has provided substantial amounts of teaching, support, supervision and advice to probation colleagues. Within the CCCS team, she has advised on risk and re-offending. Being accessible to forensic service users has brought more and younger males, who may be prone to high levels of binge drinking but are unlikely to qualify for substance misuse services. A second link worker was appointed to make links with mothers and children monitored by Social Services. The link worker works with social workers, manages a caseload of seriously unwell mothers, and runs a Mothers' Group. 'The reality is that people with personality disorders who are looking after children almost exclusively are women: the men are either gone or dead to be absolutely honest. (Helping the women by) bringing them into a group and supporting them in their parental skills but also supporting their psychological needs is a very good way of pinpointing a bottleneck of where some problems converge, i.e. if we don't deal with this these children will be, in ten years time, the next group of patients that we're dealing with.'

Service users whose condition is in remission, or who have gained as much as they can from therapy - or whose condition makes too much contact unbearable - are treated using a Reactive Input. These service users remain involved with the service, have access to the emergency contacts elements of the service, have a case manager, and are encouraged to continue to attend Lifeworks and the Community Meetings: but are care coordinated outside the CCCS. By Summer 2006, it was decided that those who were unlikely to make further change should be discharged to Life Works, along with intermittent outpatient appointments with the head of service. 'Essentially we're saying, "Let's have a go. Fly solo for a bit." There's another group where we, they are not much better or they are a bit better and we just think probably for the moment we've done the most that we can. Let's see how we go and there comes a point, you know, where pressing people to change just demoralises them.' Another staff member agrees: 'We shouldn't be holding on to them forever, because we can tend to do that and the danger is that if we do that we will become this closed service, we'll become like the CMHT, so we never have space to take anyone on.'

Despite the pressures on capacity, the service continues to advertise where it has not gleaned referrals to date: "If you ignore areas of need, you are not necessarily helping the situation, you are probably excluding the illest patients.'

Peterborough

The Peterborough service has concentrated on 'spoke' functions, developing the capacity of local mental health and social care professionals to manage service users with PD, either through consultation clinics around service users, or general training around presentation and management of PD. In addition, the service can offer a psychodynamic assessment, but has very limited capacity to deliver therapy, and so requires that service users who are subject to consultation or assessment are securely held by referring mainstream MH services. This service has only 2.3 FT staff to provide a service to a population of 200,000. One staff member spends most of his time liaising with psychiatry, chairing the consultation clinic (which was commissioned by a Multi-agency Forum), and supervising ward staff in the local District hospital (which has two psychiatric wards, so little capacity for specialisation). The Team were, during the life of the pilot, seeking additional funding from PCTs to set up a clinical service, as there is no dedicated PD service in the area. Historically, the mental health services in Peterborough have responded poorly to people with PD who have largely been excluded from services. Thus the rationale for this part of the pilot service with its tiny staff team was to improve capacity and motivation within mainstream services.

In providing consultation and support, clinicians try to work through established attachments. 'A lot of people with PD have got big attachment issues and have a lot of disruptive attachment in their life histories … so why hoik them all out of that into a new specialist service with a whole different set of people? So the overall model is along the lines of well let's see the patient in context in their existing care team; if they are in a crisis, something is happening, anxiety levels have gone up through the roof for whatever reason so partly we are there to help that environment get back to a viable level of anxiety. So we would support the care team; we would help them understand what is maybe going on and through that understanding they would be able to be less anxious, more on top of what is going on and their feeling of increased calm goes back on to the patient.'

The current five functions the Peterborough team provide are:

- A confidential consultation clinic, where specific service users can be thought about with their care team, and everybody who is involved with them. (This has involved invitation to GPs, A&E, ward staff, psychiatrists, care coordinators and housing support staff.) 'We discuss with them what is happening; what is happening with the patient, what the risks are and what the care plan should be. And that allows us to help them to see all the team dynamics surrounding the patient and get the patient properly in mind to work out what is best for them…From the work we've done across the CMHTs, that time where they can stop rushing from one thing to another for an hour and really stop and think about where they are at, what they are doing with a patient (is a rarity)… CMHTs seem to be more and more pushed towards seeing a lot of people but not for very long; getting people in through the door and getting them out again.' Seeing the service user for a separate assessment is an option. The model of discussing the service user without his/her involvement was thought strange. 'When we did the literature to be formatted into information leaflets, it came back changed, with the patient invited. What we tried to hold was that actually it is appropriate for the team to think about the patient without them present, and this models appropriate parenting.'

- As part of the consultation, a psychodynamic assessment of the service user is usually undertaken. 'So in that respect, it's slightly different from the Complex Cases, although there's a lot of similarly between CAT and psychodynamic.' However, the service feels it is a worry "getting people to go through a very lengthy assessment – 2-3 50 minute sessions – when they won't get therapy. '

- Supervisory work, both general and specific. 'We offer a regular monthly PD focus supervision to each of the principal teams within the Trust. So the CMHTs and Assertive Outreach and the Wards and so on and those are open forums where anyone on that team can talk about any patient and obviously that is focussing on that particular patient but everyone is hearing how that patient is and sees similar people within their own case load and benefits from that.'

- There is a monthly Multi-agency Forum (not confined to mental health services) which is half formal training or presentation, and half discussion of cases brought by participants. 'That MAF already had a training remit, so we pulled that out and firmed it up, and offered to agencies a once-monthly, 2-hourly slot to think about assessment, recognition, self-harm and violence, managing risk, and just ideas that come up through the floor. We did one on impact on the team.'

- In addition, the team participated in Eastern Region NIMHE training events, and have also been involved in the 10-week training, 'The Experienced Practitioner, Not waving but drowning', convened by the CCCS lead. Another course for less-experienced staff was run at the Homerton Health Centre, but could not be repeated due to limits on available resources

- As at January 2007 a small but very intensive psychotherapy service has been established. This is an 18 month service for each of up to 7 service users. The original hope was to have a capacity for 8 service users, but the manpower does not allow for this.

Among the key points discussed in the training were the following:

1. Playing down difficulties rather than over-dramatising them. 'Keep it normal, underplay rather than overplay: I think sometimes specialist services can buy into the need for drama and hype.'

2. 'Mentalisation work is about over a long period of time having some sort of attachment with the patient and helping them understand that they feel stuff; that sometimes they feel stuff pretty strongly; a lot of the time they tend to be driven to action, you know, unhelpful, harming action. Well let's recognise you're feeling something; try and switch off the immediate jump to doing something bad about that.'

3. Taking the sting out of discharge. 'We say, "Well don't discharge them just say it's fine we'll carry on." Then the way you can do it is to say, "Well I'm not going to see you every week, I'm going to see you every month or I'm going to offer you something every 3 months or whatever it is." And they are fine with that; it is when their attachment object disappears off the radar completely that the difficulties happen.' PD service users tend to be long-term. 'I think we try to get people to a point where they can get by without very much at all from services: but there is an enormous gulf between minimal input and discharge.'

4. Sharing responsibility across teams increases confidence: 'So like in the ward, you know, their model might be, oh someone is suicidal then watch them like a hawk…. Say you are in a CMHT and you feel that someone is a risk, either to themselves or to the people around them and you are sitting there on your own. It is worrying. You have a consultation clinic … we discuss it and from that we come to some sort of consensus about what is going on and therefore what we think the best management plan is. That is documented as the agreement of the consultation clinic thereby sharing the risk across everyone that was there. Then everyone can just go forward with that and to an extent that reduces the individual front line practitioner's worry.'

5. Making service user/therapist relationships explicit. 'Is it acceptable to say that this is a difficult patient? Who knows? I tend to feel that we should be more robust about these things. Not be politically correct and pretend that everything is marvelous. Hear the good side, hear the bad side of everything and then try and deal with it. … I always put on the agenda, well, where are you with this? You know, what is the state of your relationship with that person? What has happened in that relationship? How does it feel? … The fact that they get attached to you; that there are transferences, that there are counter-transferences; that a whole load of stuff goes on in the relationship. That is where the therapy happens…. You can either blind yourself to it and refuse to accept that it's the case or you can wake up and see what is actually going on.'

6. Regaining some sense of influence. 'This is part of the problem of staff, they are pushed about, don't know what's going on. The intervention with those who exhibit the hairiest self-harming behaviour …. the more you do, the more they self-harm: so back off. And that's been hugely effective…. MH services tended to see these patients as psychotic: we had in effect given them permission to see these patients not as psychotic, where they usually operate on that model of intervention…'

7. Letting the service user take responsibility. 'What happens often is the responsibility is handed over to the care staff. Getting into dialogue with the patient about the conflict within themselves about their self-destructive behaviour and enabling them to take charge of themselves again can be phenomenally useful, and that comes through the dialogue with the patient. So it's not seen as a punitive response, of not caring. It's understood by the patient, who is telling you this anyway.'

8. RAID model: reinforce the appropriate, the inappropriate downplay. 'Even in the most disturbed patients, behaviour in 85% of the time is going to be appropriate. So it's about doing the minimum to keep someone safe, but not reinforcing inappropriate behaviour.'

The Peterborough team put in a bid to the PCT for more funding to develop clinical services for service users. Initially, this was to be twice-weekly psychodynamic groups, supported by a planning group that could identify other resources, such as crisis support, art therapy or anger management. The model assumed that CMHTs often provided good support of PD service users, but not therapy. 'You can manage someone the rest of your life, but change requires long slow slog, and you need the skills and training to do it. Mostly CMHT staff are care coordinators, brokers, and the face-to-face work is done by support workers who're unqualified. You're not going to get therapeutic change in these circumstances….' The Peterborough team wanted to take on clinical work, and felt they would command more respect for their expertise if they could demonstrate it through clinical practice. Following wider consultation with staff and ex-users, a service for 6 – 8 service users to have a weekly group analytic session, plus a weekly Art Therapy session and a weekly individual therapy session was designed. There would be monthly whole systems groups where the Care Co-ordinators, all the therapists and all the service users would come together for an hour and a half; plus a weekly clinical meeting and supervision for the therapists. Each service user would be expected to stay in therapy for around 18 months. Additional funding for this service was not received, but the team decided to implement it anyway. The service lead reports that the additional resources required for this has compromised their ability to provide training, and the possibility of doing any in-reach work. The service feels that there are still gaps with the clinical service, such as how to support carers as part of the system of helping people within therapy. The team would also like to provide post-therapy support, but financial pressures, including the need to comply with the cost improvement programme means that this has not been possible.

1.5 Indirect Service Provision

Although CCCS staff are predominantly delivering direct services to service users, they offer training and consultancy to different types of services, and supervision to four or five SHOs who are on therapy placements within the psychological therapy Service.'

Staff from both services have made substantial contributions to Nimhe Eastern Regional Development Centre PD Programme, including the senior practitioner course, which was developed by the lead clinician for CCCS. CCCS also provides supervision and consultation, and 'a major part of the work done by the Complex Cases Team around each case treated is liaison with the caring network that is involved with the patient.... ' Leaflets are mounted on the Complex Cases Website (www.complexcases.org), which provides a large amount of information about the service, and hosts web pages for service users and a forum open to all who wish to use it. Staff in CCS may take on independent outreach: e.g. one provides team supervision to staff on a local acute ward.

The Peterborough service is predominantly concerned with indirect service provision to staff and professionals (described above). 'I think what the (Peterborough service) do very well is work in a consolidation capacity with CMHTs that, and we're actually in the process of developing it, because a couple of the other staff members and I have drawn up the protocol for work liaison, and our plan is that we keep in regular contact so that we will be there in kind of consultation capacity for them to talk to us about people with personality disorders … or people they feel they'd like to refer to us.'

1.6 User Involvement

The Cambridge service sees social therapy as crucially linked with user involvement. Monthly community meetings follow on from the Lifeworks' meeting. Service users are encouraged to contact and support each other and to take active roles in developing and shaping the service. A range of joint user and staff-led activities (such as a book club, a newsletter and a website) try to support this element of the work. Service users have representatives who attend key business and strategic meetings. Staff have found that 'User involvement does not come easily to this group. Furthermore, for this group of patients, 'the distinction between user-involvement and treatment is never clear-cut. Patients do not regard these two activities as distinct, and attempts to foster such a division always fail.' (June 2006 report). The team has therefore tried to foster joint activities with staff to increase empowerment. 'Patients need to feel they belong somewhere, and that we aren't doctors but more we are people who are trying to help them… We all get called by our first names by patients, and we're trying to break down those barriers.'

Service User (SU) participation is developing in the region, with a SU Lecturer; SU Co-facilitators (which have proved hard to recruit) in each county; Training for Trainers support; and representation on the service Steering Group (again this has proved hard to recruit). A user representative who comes to the business meetings once a month to bring their problems. It is recognised that there is a need to devote further attention to supporting service users involved with the training programme and in particular to develop a clear and transparent protocol for employment.

With regards to the service in Peterborough, the service has incorporated evaluation into the model every 4 months. There is one session of evaluation which takes the form of an ongoing audit, which has a focus on service user feedback. Other than this, the service have mainly involved ex-service users from the Henderson in a consultancy group for service user input. The aim of using ex- rather than current service users was to protect the therapy experience of current service users, as the service felt it may be expecting too many roles from them to also involve in committees etc.

2. Achievements and capacity of the services

The Cambridge Service delivers a comprehensive specialised service to PD service users with realistic user-led goals, which was not previously available specifically to this client group. 'One of the big benefits and strengths of the Service is that we avoid admissions: rather than someone get admitted they come here and talk to someone, and we ask them to come in every day to open clinic … There was such a huge drop in admissions and contact with GPs and psychiatrists and that was costing the major savings for the Trust, and for the NHS.' The CCCS delivers around 70 assessments per year; with 50 new entrants into service each year, and around 80 in treatment at any one time, it is clear that they have reached capacity. The Probation Link Worker may be involved directly or indirectly with 50 probation clients per year. Despite the low rate of move-on, the team managed to avoid a waiting list for some time by adjusting the intensity of the service to need.

The Peterborough team feel they have had particular success in reducing the use of MHA sections to detain PD service users; diverting service users away from long-term residential care; and in remodelling risk management among Trust staff (especially around self-harming). Between Jan 05 and June 06, there were 55 service user-related requests to the service, and 24 service users received assessment or consultation. Through follow-up of consultations, the team may be linked to casework with around 50 service users at any one time. 'We have already saved (the PCT) a potential loss of £180,000 for someone who was heading for a semi-secure private hospital. She's now discharged. That's influenced them a lot. Another one recently was heading toward a TC and will be discharged: kicking and screaming. She'd been an inpatient 2 years, and the other one 18 months. So they are valuing us: just for consultation.'

'The fact that they have a PD service has meant Peterborough has had to revise it's referral criteria. They weren't overtly excluding PD (from mainstream mental health services), they just didn't include it: you had to have an Axis 1 disorder to qualify. They've had to revise it as it would be silly to have a service for something you didn't treat.' Personality Disorders were formally accepted as inclusion criteria in the Peterborough Division of the Trust in January 2005.

3. Departures from original specification: drivers & impediments

The original bid ambitiously aimed to provide hub and spoke services in Huntingdon and the Fens: in essence only Cambridge and Peterborough have services, and Peterborough is still trying to access funds for a more direct clinical service. The Peterborough service is therefore providing a lesser service than anticipated in the bid (see description above) although it is building a clinical network in Peterborough which previously had no dedicated PD service. The Cambridge service had not (in Summer 2005) developed crisis or out-of-hours services, and has found it difficult to develop user involvement beyond involvement in individual care planning. Although attempts to involve service users continue, neither service has yet established a group for non-professional carers.

4. Findings from local audit and evaluation

The Peterborough service carried out a 360 appraisal in 2006 with staff who had used their service. 10 people (CMHT team leaders, CPNs and ward nursing staff) participated in semi-structured interviews about their experience of the service. Different staff discussed their experiences of the consultation clinics, the multi-agency forum and supervision. Supervision appeared to have been particularly well received, staff found the multi-agency forum very helpful and the consultation clinics generally very useful. Perceived strengths of the Peterborough service included that they were approachable and worked well with local teams, that they offered an alternative way to view working with service users, there was now somewhere to go with service users with PD and that they were able to offer support and 'backup' to staff. Perceived areas of weakness were that there was no direct clinical service (this has since been implemented), that sometimes workload was seen as increasing for staff, that the service did not have enough capacity to make a big difference and that local staff were not always clear as to what the service was offering. There were also suggestions for adding in more training, more supervision to ward staff (now both increased) and a wider range of interventions. Most felt that their practice had changed for the better since using the service (more confident, more secure and more aware). The majority felt that it would be a big loss if the service were to close, though some felt the impact would not be great as they were still doing direct client work with the service users.

The Peterborough service have identified that the service has prevented at least two service users being placed out of area for treatment. Out of area placements are estimated to cost between £150,000 and £200,000 per service user per year, so this represents a significant cost saving on its own. There are likely to be other areas of cost saving such as reduced use of other services.

5. Areas for future development

Future priorities in Peterborough are the development of a direct clinical service (see above), requiring at least one more fulltime clinician and additional admin and research support. In addition, Peterborough wanted to focus on developing a PD capable workforce, by reinforcing the commitment of Trust staff to this group. The Training of Trust staff would require Trust commitment to train new staff and support refreshers: 'It fits in with Trust policy (to increase retention and reduce reliance on bank staff): if you give people this sort of input, their attachment to the organisation increases phenomenally.' Peterborough also hoped to pilot a primary care psychotherapy service for up to 6 service users.

The trust in Cambridge and Peterborough is in the process of reconfiguring. This has led to pressures for both parts of the services to increase the catchment area they serve. Cambridge is being asked to extend into Huntingdon and East Cambridgeshire and Peterborough is being asked to extend into the Fens. In order to achieve this with the same model, both parts of the service would need greater resources. Peterborough is in the process of submitting a proposal for additional resources. Cambridge is also putting forward a business plan as to how the Cambridge model can extend. Both parts of the service feel that an important achievement is that PD is now seen as an important part of the services that the Trust provides.

6. Summary of lessons learned by service providers

- Close integration and liaison with those who decide on funding is important. Link workers who facilitate communication with other service components are also important.

- At the outset of the pilot, the service put a strong emphasis on giving people group and individual therapy as the main aim of the service. Now there is a stronger focus on developing a long-term attachment to the service through Lifeworks, a part of the service providing group activities, social support and open clinics.

- The assertive outreach element of the service is an important element. The service will follow up when the user has not attended or has inconsistent engagement, through a variety of methods including e-mail and Open Clinics.

- A 'zero tolerance' approach to self-harm when engaging in therapy is important. Although patients sometimes do not like this, it is felt to be an important part of safely engaging with therapy.

- In Peterborough, not starting with the clinical service originally allowed it to put a systematic structure in place for supporting care coordinators to work with people with PD. This provided an environment where the clinical service could develop and retain their full support.

- Advising and supporting existing teams is important because it minimises disruption to the client's attachment relationship to their team; supports the expertise already in place in CMHTs; maximises the benefit of limited psychotherapy resources; drives culture change; and reduces stigma.

- Having an explicit patient pathway based on a recovery model is key to achieving improvement. Therapy approaches should be multi-modal (i.e. provided in different formats), but underpinned by a unifying model.

7. A Summary of Service Users' Views (Cambridge only)

Nine people were interviewed in Cambridge, seven of whom were current service users, one a past service user and one a carer. Six of the current service users were women, and the rest of the interviewees were men. Interviewees had been in contact with the service for between one and three years. They had used a range of groups and individual therapy, open clinic, relationship therapy and telephone support. Research participants were recruited using flyers, presentation to a community meeting of service users and staff and staff follow up invitation. Volunteers were then contacted directly by service user researchers to arrange interviews.

Referral and expectations

Most of the service users were referred to the Complex Cases service by their psychiatrist or psychologist. Most said that they knew very little about the service before their first appointment, other than that it provided talking therapies. (Since that time a leaflet has been produced and there is also a website).

Most service users talked of their desperation for help and a willingness to try anything; most had found other mental health services unhelpful. Consequently they expressed few concerns about coming into the service, although a couple of people were anxious about taking part in group therapy. The service users were hoping that they would have the chance at Complex Cases to have access to talking therapies and a chance to understand themselves and their feelings better.

Assessment

People coming into the service more recently had found the assessment process rather daunting; it was very thorough and had inevitably focused on their problems and past history. The process is more formal now than it was in the early days of the service, and entails interviews, tests and a case review with the service user, family members and relevant professionals present. Nevertheless, service users found the staff to be reassuring and friendly.

Support from the service

A number of people found the individual therapy difficult; painful issues were discussed and therapists could push people quite hard. Whilst this was thought necessary for the therapy to be helpful, there were a couple of people who had found it distressing and unhelpful at times. A few people expressed concerns about the ending of therapy, although these had largely been allayed by the service; a couple of people had been offered the opportunity to re-start therapy if in a crisis. Group therapy was also found to be difficult at times, especially when having to cope with other people's distress. However, service users valued the benefits of mutual support and understanding between group members.

Service users valued the daily 'Open Clinic' for the opportunity it provided to access support Monday to Friday at 9-10am. Similarly they valued being able to email their therapists at any time; this was found useful as a follow-up to sessions and an emotional outlet out of hours.

Some service users were concerned about the lack of support available to them out of hours especially in a crisis when they would have to go to A&E or call the duty psychiatrist. A couple of people were critical about how individual crises had been dealt with by the service.

Support for carers

Several interviewees said that family members can attend the care reviews and some carers had been told that they could use the Open Clinic. Nevertheless, it was suggested that more support for, and involvement of, carers was needed.

Relationships with Staff

Service users placed a high value on the relationships with staff at the service. They described staff as open, accessible, friendly and trustworthy and said that staff made them feel secure and cared for. Several people said they could phone their therapist at any time and most also used email to contact staff; responses to both were prompt, usually within the day. The helpfulness and knowledge of the administrative staff were also praised.

Involvement

All service users felt very involved in planning and deciding their own care. They can attend their care reviews and a form has been developed to help them decide what they want from the review. In general, service users felt that they do have a voice in their care reviews and that their opinions are listened to. User involvement in the service as a whole was less developed at the time of the interviews. A monthly Community Meeting is held, but at the time of the interviews these were poorly attended and some felt that the meetings were difficult to participate in, and resulted in little change.

Peer support

Sharing experiences and ways of coping with people who have similar problems and who understand each other were thought to be particularly helpful. A number of service users had made good friends through the service.

Outcomes

The majority of the service users identified some clear outcomes or changes since beginning their contact with the service. A number of people talked about developing a better understanding of themselves and how they think and feel. Some felt they were more open and honest about their feelings. Understanding and managing feelings of anger were mentioned, and several people reported a significant reduction in self-harm. Interviewees talked of a better quality of life and improved relationships with family and friends. One person said the support of the service had helped her to remain in work, and three had taken up college courses. People tended to attribute these changes to the overall ethos and approach of the service, pointing to the encouragement, perseverance, trustworthiness and flexibility.

Some people felt that the service had made things more difficult for them in certain ways. This was partly due to the emotional demands of psychotherapy, although some people pointed to specific occasions when they felt their therapist had not been sympathetic or understanding, causing unnecessary distress. There was also a feeling that the service focussed on people's flaws and did not take into account individual strengths.

Suggestions for Improvement

Service users had a number of suggestions for improvement. Several people felt that the timing of the Open Clinic should be changed or varied, and some felt that the evening telephone clinic should be extended to every night. There were a number of ideas to improve the provision and organisation of activities in the Lifeworks group.

Some people felt that more effort should be put into the community meetings, in order to make them less daunting and encourage more people to attend. A buddy scheme for new service users was thought to be a good idea, and other suggestions included more social activities, a retreat facility, service user-run drop-in centre, and help with practical issues such as money and form filling. There was also concern about the accessibility of the service; it was not thought to be well publicised and it was suggested that people living in rural areas need a more local service.

A5 The Haven

1. Description of Service

1.1 Aims of pilot service

The Haven aimed to provide (from the Bid):

- 'An accepting and safe environment, a community that will instil a sense of ownership for service users…Open 24 hours 7 days a week….

- A day service, offering practical help, support, friendship and a range of informal and formal therapies;

- A crisis centre service offering, out of hours, a refuge and support during times of immediate and urgent crisis.'

The Haven aimed to take 100 service users out of Trust services; and to collect data on 65 service users to demonstrate savings to local services.

1.2 Staffing the service

In 2005 there were effectively two staff teams, day services and crisis (overnight) services, led by different managers. In response to splits between day and night-time teams services were reconfigured in Spring 2006. All staff now work with people in crisis, although the team covering 24 hour shifts carry out most of this work. The crisis service offers a safe centre (for up to 6 service users for 5 hours maximum each) and 4 crisis beds (which service users can occupy for up to 3 weeks). Apart from the Service Manager, crisis workers are not medically qualified, though their prior knowledge of service users can enable astute assessment. They can refer on to the Acute Psychiatric Trust if necessary. Running the crisis service at all hours is difficult and expensive. There must always be two staff on duty in the out-of-hours crisis service. If one worker is in a one-to-one session, another must be free to answer phones, the door, and manage crisis bed and safe centre clients. There are three staff on duty during the day, Mon-Fri: a project worker for shifts who covers 9am to 5pm, Mon-Fri, and two project workers cover every other shift out of hours. This means that all of the team get to work with each other some of the time. The length of shifts has also been changed to 12 hours rather than 8 hours.

The Chief Executive of the service reports that these changes have been welcomed by those working shifts as they can often achieve their week's hours in 3 days, leaving the remaining 5 days of the week free. By Summer 2006 the service employed 2 staff to cover day shifts. One a project worker and the other an assistant service manager, who is a social work graduate. The team is also augmented by two social work students who are on placement for 10 months of the year and augment the day service, as well as working some evening shifts, supernumerary to the 2 project workers on duty. Four volunteers also work at the haven on day services. Project workers covering the crisis service are also involved in some day services e.g. helping to run the DBT group, swimming at the Health and Fitness Group, and facilitating the Substance Misuse Group and the Gardening Group, which gives them a flavour of other parts of the service rather than continual crises.

Most staff do not have professional qualifications, although the Head of Crisis Services is an RMN on secondment from the local Trust. However they have relevant experience, e.g. in hospital, housing support, bail hostels, counselling training, etc. The personal qualities of staff are held to be more important than formal qualifications: it is difficult to know at interview how resilient staff will be, and the service has had to let go some staff: 'With … those staff you are looking at a personal vulnerability that resonated with something in the client group that made it impossible for them to be here.'

All new staff are provided with induction training. In addition to this, existing staff were to have ongoing training, plus clinical supervision by North Essex Mental Health Partnership Trust Psychology Department. Original shift patterns made it difficult for staff to attend training and supervision, but changes instigated in Spring 2006 facilitated this process. Problems in relationships between service users and staff including some serious boundary issues led to further staffing changes. Questions for recruitment interviews have been redesigned in an effort to test applicants attitudes to boundaries and questions have been added to a revised Job Application Form and a Reference Form, enquiring about time off sick and whether the candidate has been subject to previous disciplinary action. The Chief Executive reports that the staff team now feels much more resilient and open: 'We don't always agree, but we feel this is healthy'. Boundaries are a very frequent topic for team discussion and are kept constantly under review. A new policy was created in 2006, in consultation with staff and service users, called Risk, Boundaries and Equity, making the pitfalls explicit.

1.3 Client group and referral process

The Haven differs from some of other pilot services in that it does not diagnose during assessment but accepts service users already diagnosed with PD. Criteria for registration are of relatively low threshold, and 'priority' criteria are not applied. The service users exhibit a mix of severity of pathology, which may be useful, as service users may be able to see models of progress in each other. The Haven has retained almost all the service users it has registered (exceptions being the handful who moved away, or were expelled for unacceptable behaviour). Haven had approximately 110 service users at the October 2005 and June 2006 reviews, 80% of whom are expected to receive at least one of the Haven's services within any one week. By September 2005, it was decided that no more referrals would be accepted (in preference to holding a waiting list). The Haven did not know how they would deal with future referrals; but staff feared that closing their doors to new registrations might reduce their 'value' in the context of local statutory services.

Criteria for registering are residence within 25-mile radius (as ability to get to the service during crisis is needed); and a PD diagnosis at some time. The type of PD is immaterial: categories are anyway disputed. There is no exclusion for co-morbid Axis 1 disorders, but only four service users had a psychotic illness (Bipolar Affective Disorder in two cases and Schizophrenia in two cases). Eating disorders and substance misuse are relatively common. The service user must want to use the service. Those presenting unacceptable risk to other service users are excluded. On first opening, two managers brought around 50 service users from acute services where they had worked. Most referrals now come from CMHTs: despite leafleting, few referrals have come from general practice. It is accepted that there are four or five service users known to local services that 'have never been referred and I don't know what we would do if they were … I think the consultants are being kind and realise how disruptive they would have been.' The Haven was over-subscribed, and had to close to registrations between September 2005 and January 2006. Since then limits on the number of registrations have been set (at no more than 2 new registrations per month). This in turn led to a small number of people having to wait to register following their initial contact with the service.

1.4 Model of intervention, expected outputs and outcomes

The Haven is a large attractive house with garden in a residential area in Colchester in Essex. It offers activity groups and one-to-one sessions, and a crisis service running 24 hours a day, which comprises a Safe Centre where up to 6 service users can take refuge at any time of day or night, and 4 full-time crisis beds. A crisis phone line is also maintained at all times. Registered service users can use all facilities. Day Services were started in August 2004 (and the programme of group work started developing). The Safe Centre opened in November 2004, prior to moving to the current premises, and the crisis beds were opened at the beginning of February 2005. The Haven also offers in-house benefits and housing advice, a limited number of counselling sessions, a range of groups, and has many links with other local sources of support. Service users can have support telephone calls and one-to-ones built into their care plans, and can call the service at any time for support. This is the only pilot service that runs 24/7 face-to-face services.

Haven does not take on care coordination, though it does work with Trust personnel and supports CPA: most service users are thought to be on CPA. Service users may have contracts and care plans detailing current issues and the support they may expect from Haven. Therapy takes place in several situations. During the daytime, service users can attend specific groups. During days and evenings they can have time-limited one-to-one attention from staff if this has been scheduled. At night time, they can come in and use the Safe Centre for up to 5 hours, which is likely to include a one-to-one session. They can also come into crisis beds (to which access is pre-arranged) for respite. Care planning is a key aspect of the Haven service, negotiated between service users and staff, and reviewed according to events. Service users sign contracts to abide by house rules, and these may encompass some of their personal goals, such as reduction in self-harming. At the start of the pilot some staff felt that care planning for service users was too vague, and their use of the service too open-ended. They felt that service users might be very institutionalised and needed pushing; and that the future capacity of the service was dependent on moving people on. 'Our clients are anxious that we may deregister them before they are ready. But we can't give support forever to everyone: project will have failed if we can't move them forward….' Set against this was the risk that service users who were pushed too far too fast might feel rejected. There was also a lack of specificity to the one-to-one sessions, which were led by service users, did not apply any particular model, and were not monitored.

In an effort to address these concerns it was decided to initiate a weekly meeting where a longer term view of service users needs could be reviewed. These meetings are called Progress Planning meetings, a name that was suggested by the service users. The meeting is open to all staff and, whether they make it or not, the minutes are distributed to all staff and bank workers weekly. All staff take turns, individually, to prepare a history and their reflections about one service user per week. This comes to the Progress Planning Meeting and the staff at the meeting work out a formulation and their suggested points for a Long-term Care Plan. The Preparation Sheet and Minutes are the only information the service keep confidential from service users and staff feel this allows real clinical space to express opinions e.g. they might want to say that Service user A is always threatening suicide but has never made an attempt. Ideas from Progress Planning are taken to the service user and a Long-term Care Plan meeting is held with that person, and staff member and service user collaborate on the plan. The plan usually includes their future aspirations, as well as addressing current difficulties in a long term way. In recent months, there has been an internal review of service users' use of beds, phone line and 1:1s and has resulted in valuable data for discussion in Progress Planning Meetings. The service have also now instituted a new approach to social inclusion called Transitional Recovery, which will be discussed further.

The underpinning model of the Haven is that of a supportive community. 'Community is friendship and supporting each other as a group. We are a kind of united front, fighting for each other'; 'The Haven as a community is like the family I never had. It's a place where I feel safe and able to explore my path to recovery.' (service users, quoted in Haven report, June 2006). The service is engineered to discourage one-to-one attachment (in favour of attachment to the Haven). However, at the same time, the relationship of service user to the service is seen as one of trust and attachment, so a difficult balance is attempted. There is no key-working system, although service users have said they would like one. The staff team hold the service users. 'We did have for quite a long time one-to-ones being assigned to particular staff and we had clients asking, who's on shift tomorrow: but we've knocked all that on the head because that was more attachment issues really, clients finding ways to always have their one-to-one with their favourite staff member.' This makes notes very important, and staff are good at them. 'Note keeping is excellent. It's absolutely brilliant and the handover is equally so. It's excellent continuity.' Service users have open access to their own notes.

Both service users and staff have broken boundaries, and this has motivated several staff dismissals or resignations during the life of the project. A new volunteering policy has been drawn up to cement the distinction between staff and service users: those who work (paid or voluntary) are not allowed to have a PD diagnosis, nor to register as service users in the future (which acts as a deterrent to volunteering and protects confidentiality). The service does, however, employ staff who have personal experience of PD as a service user or carer. Boundaries between staff and service users are a matter of balance: staff do not want to appear superior or judgmental. 'One of the nice things is that some of the staff smoke: people are on the same level. Staff eat lunch in the kitchen: there is not the 'them and us' thing.' Key boundary issues for service users are behavioural policies, and the policies detailing limits set for staff time and attention, and attendance at the project. Service users themselves jealously guard the operation of such policies and complain about any infringement which unfairly favours others. Many service users seek individual attention from staff, and may go round the whole team trying to get someone to agree to a one-to-one. These are usually limited to thirty minutes, and should be planned unless a service user is in crisis. Those in crisis beds are entitled to at least one per day. Telephone support calls are likewise limited to 30 minutes. As is common (among the PD pilots), staff working with this client group may often disagree about how strictly behavioural boundaries should be reinforced.

Some staff have felt more emphasis should be placed on moving service users on, and 'handing back responsibility', both to ease the capacity constraints and because this is a worthwhile treatment goal. One way in which the Haven has tried to open up the issue of moving on is through discussion of 'recovery' - what might it mean? Within the context of the 2-3 year pilot, there may well be stages to recovery. 'There's loads of our clients who've just decided they want to live. That's the stage they've got to, "Oh I want to live now, I don't want to die".'

Group work:

Group work at the Haven is not fixed, and new facilitators are generating new programmes. External facilitators are paired with Haven staff so management can be transferred to Haven. Most groups are open to all comers on the day, although a maximum of 15 participants is written into the planning permission for use of the building. The DBT group is the one which is most closely associated with therapy and it has been running since April 2005. It is a closed group run by a psychotherapist from the local NHS Trust and a Haven staff member who is a psychologist. Staff report that some users found DBT difficult within a large group, and would prefer one-to-one DBT sessions, which some have experienced elsewhere. The Trust required that 8 people should be selected for DBT, and, originally, that all should be on the Trust's waiting list for DBT. The DBT approach is therefore confined to participants in, and context of, the group. Some service users continue to have other therapies from the Trust's psychology service, but the Trust decides who has it: Haven has advocated for some of their service users to access to such therapies.

Friendship groups are run twice weekly. One staff member does 'pampering' sessions in the lounge during the group (nail-care and head and hand massage), which is thought to be beneficial for people who don't value themselves. If there is no staff member to run an activity group, the attending service users are asked if they would like to run it. Service users agree that is empowering, but also recognise the role of staff: 'It is quite important at the groups that you do have a member of staff mingling because they tend to quell undercurrents that may be rippling'.

The service has introduced different types of group: some encourage psychological thinking and promote skills to improve impulse control and anger management, and offer skills and strategies for 'better living'. The Haven also values creative expressive activities (such as creative writing): these may also be quite personal. A health and fitness group is held. As the earliest recruits mature, it was recognised that there was a need to plan to expand support available to service users going into work or education. This is part of the wider need for interventions which help people move on.

Crisis support:

Phone contact, both planned and unplanned, has been more important to crisis support than had been expected (as there is a local phone support service run by Maldon Mind). 'But if you look at continuity of care and of course the telephones are stopping people coming in (so potentially reduce demand on the service) … care plans include support calls and they know they can call us… So now they've got a separate line for crisis calls and that is checked every half hour and the message on that says that we will endeavour to get back to you within half an hour and also it's a cordless (so staff are not called away from other service users).' Service users ringing in are assessed over the phone, and can be invited into the Safe Centre (a low lit room with comfortable seating) in which case they can be offered collection by paid taxi. Crisis support aims to be 'preventative' rather than reactive. Over-use, e.g. of the safe centre, is monitored, and workers may suggest someone learns to cope with phone contact instead. Service users should only stay in the safe centre for up to five hours at a stretch.

Surprisingly, the crisis beds are usually booked: people are able to manage a period of waiting for their allocated slot, and the beds function as respite beds. 'There is planned admission type… whereby clients who have a particularly bad track record of self harming or suicide will be given a bed at intervals through the year to provide them with opportunities to work through all the issues they're struggling with and also to have literally respite care really away from the pressures and circumstances they're living in.' These are essentially preventative cases; at other times, the crisis beds are used as a substitute for hospital admission. A person can stay for up to 3 weeks in a crisis bed, but should be away for a month before the next stay. Only the Service Manager and her deputy, can decide on how the beds are allocated, and this prevents manipulation and lobbying by service users. Service users have to show they can progress by having a crisis bed, and have care plans incorporating one-to-one work. Beds may be used to break self-harming patterns, and service users are ejected from crisis beds and/or banned if they self-harm on the premises. By 2006 the Chief Executive reported that the beds were now almost always used for preventative respite rather than in the acute management of crises.

Impromptu meetings called 'Community Discussions' are called to resolve disciplinary matters, which removes the pressure from the staff to enforce the rules. While on the premises, service users manage their own prescribed drug use as they would at home. 'Occasionally, very occasionally we simply cannot hold it: we recognise our limitations. Sometimes (the problem is) getting the local services to recognise our limitations.' Community Discussions became more frequent during the period of pilot funding (currently happening 2-3 times per month) and are one of the main ways for staff at the Haven to deal with any serious issue of difficult behaviour in the client group. The person under discussion is invited to the meeting or the discussion in anonymised. In relation to local service liaison, during 2006 the Haven formed a Joint Protocol between Crisis Resolution and Home Treatment Team and the five Community Mental Health Teams. Liaison is usually good and any requests from The Haven for an assessment for hospital and/or a Mental Health Act assessment is usually treated with respect.

1.5 Indirect service provision

Although the Chief Executive undertakes promotional and training activities, and the Haven holds open days which have received hundreds of local and national visitors, this service does not have a formal commitment to such activities and could not undertake them with the current staffing levels. There is joint working particularly with primary care staff and staff of mental health services and A&E.

In addition to this the Chief Executive, and Haven service users, attend and present at a number of National and local conferences. The Haven is also considering a North Essex PD Forum or Conference and has aspirations to make this an annual event.

1.6 User involvement

The Haven model was directly based on local focus groups held in June 2003, building on feedback from service users. Formal user involvement is centred on The Haven Advisory Group which meets on a monthly basis. The Haven Board of Directors is made up of ten people, five of whom have used mental health services. Those ten are also part of the Haven Steering Group which also includes other multi-agency partners, statutory and non-statutory. The Board and the Steering Group meet every two months. The Chief Executive also runs Service Evaluation Groups (SEG) every 3 months which are recorded and transcribed. There is also a Quality Governance Sub-Group with service user representation. Users have been involved in key areas such as consultation on all Haven policies. Elements of service user-led democracy are present throughout the activities of the service. Staff at the Haven have reported that these aspects of the service together with the closeness of community living have the potential to blur boundaries between staff and service user: staff therefore need to be particularly assiduous about their boundaries.

2. Achievements and capacity of service

Staff told us that the service is highly valued by service users, who have had, and continue to have, a major influence on its development. It provides support to around 110 registered service users at all levels of disability. Staff at The Haven report that service users find the service a very 'validating', empowering environment. They do recognise, however, that user power can become dysfunctional, perhaps by affecting safety and containment. Haven has an honest approach to raising and discussing these issues, and the willingness of managers, staff and service users to discuss these difficulties make the Haven a centre of innovation and learning.

Maintenance of a flexible, accessible, user-friendly and safe crisis service is a huge achievement, which none of the other pilot services attempted. All staff, and not only those who work unsocial hours, contribute to crisis services. The Haven had a particularly difficult task in combating opposition to planning permission for the Service. Maintaining good relations and firm boundaries (around noise, smoking, parking, numbers using the house at any one time) with their neighbours has been a shared concern (and success) of both users and staff.

3. Departures from original specification: drivers & impediments

During the period of pilot finding a greater emphasis has been placed on the therapeutic programme offered to service users at the Haven. While the therapeutic community nature of the project is believed in itself to be therapeutic the day programme now includes a rolling 13 week Life Skills Programme, Substance Misuse help and groups like Creative Writing. Staff skills have been enhanced by workers attending PD Master Classes in Cambridge which seven staff attended in 2006. A recent initiative has been to buy in expertise for whole team training. In November 2006 training was provided by Deanne Jade lead for the National Eating Disorder Association and in February 2007 there will be a training session for all staff on CBT, taught by the Eastern Region Therapies Lead. The service intends to continue three monthly staff training in this way, ensuring that requests from the team form the agenda.

Staff at The Haven have always been concerned that words such as "discharge", "through-put", and even "study" and "work", can unsettle and undermine service users with a PD diagnosis. However the service has developed a new category of service user using the service called Transitional Recovery and such service users aspiring to join this category are able to attend a weekly Transitional Recovery Group. When people graduate to this category they will not be using crisis services and will have minimal contact with the service, but they can still stay registered as a safety net should they wish. The idea is that the Transitional Recovery category is something a service user is proud to graduate to. So far 19 service users have signed up to the group and are focussing on what their next individual step is. For some this is voluntary work, others are beginning pre-access courses, or working on literacy and numeracy at the group. Use of recovery tools like WRAP programmes and DREEM tools are also proving popular and helpful.

Use of the crisis phone line has been much greater than expected (especially as there is a good mental health phone line in the area). This has generated more work (both in managing incoming calls; and in building phone calls into crisis care plans), but has been a useful way to manage crises among this client group in a dispersed population.

4. Findings from local audit and evaluation

Analyses submitted in the report to Dept of Health of June 2006 estimate, based on the reduction in use of NHS services of the first 50 service users registered, extrapolated to actual 110 registered, that the service has saved £0.5million after the costs of running the Haven. The reduced use of services that this was calculated from compares annual service use for the two years prior to using the Haven and the annual use since joining the Haven. Examples of service reduction are an 85% reduction in in-patient admissions, a 78% reduction in use of the crisis team and 45% reduction in A&E attendances.

5. Areas for future development

The Haven is an innovative service and while many of the concepts which underpin it derive from the therapeutic community model there are important differences between this and those pilot services which operate as day TCs. In the words of the Chief Executive the model of service provided is 'The Haven Model'. While this model is based on feedback from local service users and has many features that are believed to be important when working with people with PD, it has not been documented to the extent that other treatment approaches have been (for instance DBT, MBT etc). This does mean the approach is less structured and evidence-based, and also means that staff are required to respond intuitively to service users and their needs. The success of this, to some degree needs to be proven in relation to other models. Longer-term internal research is being carried out by the Chief Executive which is aiming to map processes of recovery for PD in relation to 'The Haven Model'.

From its inception The Haven has had a strong commitment to providing services for people with PD over long periods of time, but pressure to remain open to new registrations and feedback from local commissioners and DoH have led to the development of less intensive services for those who have achieved greater levels of stability. The outcome of these developments may have implications for the future capacity of the service and its ability to meet demand from local services. However, the Chief Executive remains confident that sufficient progress is being made to ensure they can accommodate ongoing referrals.

6. Summary of lessons learned by service providers

- When there is evidence that boundaries have been broken by staff, act quickly, be ready to use disciplinary procedures in order to enforce boundaries

- Developing and delivering innovative services to people with PD is a challenge; but it is possible to learn and benefit from facing these challenges; 'We have really learned the hard way and it almost broke us. But, as they say, what doesn't kill you makes you stronger!'

- Rewarding positive progress and engagement results in further positive progress. Constantly responding to crises only means people have to go into crisis to get attention.

- The Haven Acceptable Behaviour Policy means that boundaries are known, understood and democratically addressed. This has resulted not just in a safe project, but also in clients learning more positive coping strategies.

7. A Summary of Service Users' Views

At the Haven in Colchester, individual interviews were carried out with 8 current service users, one past service user, and two carers. Of these, four were men and the rest were women. One focus group was conducted, comprising six women and one man. Interviewees had been in contact with the service for between 10 months and two years (since the service opened); they had used a range of groups, DBT, telephone support, crisis beds and one-to-one therapy. Project staff recruited participants according to the research sampling strategy using flyers and follow up of researcher onsite visits.

Information about the service

Many of the service users had found out about the Haven directly from [the manager of the service], who formerly worked as a mental health advocate. Others found out through their CPN, solicitor or through their own research.

Diagnosis

Interviewees talked about making sense of the diagnosis for themselves, and about an emerging sense of identification with other people who shared the same diagnosis; for example, saying that they were able to understand each other, were sensitive to each other, and no longer felt alone or unusual. It was clear from a couple of the interviews that having a PD diagnosis had become desirable in the sense that it was key to accessing the support of the Haven.

Support offered

Interviewees described using many or all of the sources of support available at the Haven: crisis beds, safe centre, phone support, groups, care plan reviews and 'one to ones'. The immediacy of support was appreciated by many: the ability to phone or text the Haven for support day or night, with phone calls returned within 30 minutes (usually more quickly). Flexibility was also appreciated; clients had booked one-to-ones and phone support calls, but could also access unplanned support if needed.

Rules

Some service users commented on the rules at the Haven, for example: no self harm on the premises, no talking about self harm or other possible triggers for people (such as alcohol or drugs) and no taking medication in front of other people. The general consensus was that these policies were helpful and contributed to an overall sense of safety. Reasons behind the rules were explained to people, and they could be negotiated in the community meetings.

Relationships with Staff

The service users generally rated the staff very highly; they described them as understanding and empathetic, able to have a laugh, good at listening, accepting, non-judgemental, easy to talk to and 'clued up to the hilt' about personality disorder. They also appreciated being able to express a preference for speaking to certain members of staff whilst being encouraged to respect the team approach. In addition, many referred to the sense of equality between staff and service users, and the sense of community (not 'them and us', staff and clients working together). The strong presence of the service manager also came through in the interviews.

Relationships with service users

Most interviewees talked about the value of peer support. For many, this sense of being 'a family' or 'a community' was a significant part of the Haven experience. Meeting others with similar experiences and with the same diagnosis, finding that it was possible to 'be yourself', giving and receiving support, all went towards creating a positive and welcoming environment. However, a couple of interviewees said it was difficult to feel part of the community as they were unable to attend frequently, either due to geographical distance from the Haven or to outside commitments.

Involvement

Involvement in the running of the Haven was a key theme. Most service users felt that they made, or strongly influenced, decisions about the running of the service. They talked of participating through community advisory meetings, the suggestions box, interviewing new staff, or taking part in the research group. Interviewees felt they had a high degree of involvement in their own care, and talked about care being individualised and about their decisions being respected. In addition, some service users had been able to facilitate groups which had made them feel valued by the service.

Outcomes

Almost all of the service users said that their expectations had been exceeded. They talked about significant personal outcomes, for example, stopping drinking, reduction in self harm, getting out of the house, getting back to work, leaving hospital, making friends, being able to talk about their problems, developing trust in others. Most of them felt differently about themselves as a result of the support received at the Haven, including increased confidence, self esteem, self belief, and a sense of hope for the future. Some also talked about finding new ways of thinking about their problems, developing new ways of expressing and managing emotions, and noticing early warning signs. The service users identified a number of different aspects of the Haven that they felt had facilitated these changes: the impact of attending groups, the experience of DBT (dialectical behaviour therapy); the staff and their attitudes, feedback or care; and the social network provided by the Haven.

Carers' perspectives

The carers were both very appreciative of the support provided to their partners by the Haven. Both expressed the wish for more support to be made available to carers: education and information about personality disorder and such aspects of care as DBT, suggestions for how to help their partner and the opportunity to meet with other carers.

Diversity

A couple of the male service users and carers raised concerns about the gender imbalance being potentially difficult for men coming in to the service. In addition, concern was expressed about a perceived imbalance in sexuality: the fact there were many lesbian women who were open about their sexuality might be difficult for some heterosexual women.

A6 Thames Valley Initiative (TVI)

1. Description of Services

1.1 Aims of pilot services (from bid)

A 'functionally and geographically tiered service', comprising:

- Oxfordshire Complex Needs Service, a hub and spokes model comprising a specialist PD team based around a day unit, intensive outpatient spoke services, with both engagement groups exploring alternatives for service users, and preparation groups for entry into a full-time TC;

- In Berkshire, specialist facilities for those not ready/suitable for Winterbourne House TC;

- A hub service based in Aylesbury, offering a 3-day TC facility, and supplemented by Options Groups.

1.2 Staffing the Services

There are four programme leads within TVI, one for each county and one for the TRRT (Training, Research & Recovery Team), which works across the three counties. The Thames Valley-wide Training, Research and Recovery team (TRRT) continue to focus on training and the development of ex-service users and 'experts by experience' to develop personality disorder services. The TRRT team consists of: 0.2wte Programme Director, 0.6wte Programme Manager, 1wte Programme Administrator; 0.5wte training co-ordinator (funded from non TVI money) 2.2 wte expert by experience posts employing up to 8 people (two with a research specialism).

The Oxfordshire team consists of 1wte Programme Director; 1wte Team Leader; 1wte Deputy Team Leader; 1wte Senior Team Therapist; 3.5wte Team Therapist; 1wte Team Psychiatrist (staff Grade); 1.5wte Specialist Team Therapist (split into 4 part-time Posts); 0.7wte Assistant Team Therapist 2wte Administrator, a total of 12.7 wte. The Berkshire team consists of: 0.5 Consultant Psychiatrist, 0.1 Specialist Registrar, 1.0 Senior House Officer, 0.3 Senior Manager (Programme Director) and 3.5 wte therapists, a total of 5.3 wte. The Buckinghamshire team consists of: Joint Programme Director 0.2wte, Consultant and Joint Programme Director 0.7wte, Team Leader 1.0wte, Senior Team therapist 1.0wte, Senior Team therapist 1.0wte, Team Therapist 0.3wte, Assistant Team Therapist 0.6wte and Administrator 1.0wte, a total of 5.8wte. Regular joint management meetings take place across the three counties, and a forum is in place to bring the three teams together every six months, to aid in the process of service development, consolidation and vision for the future. The integrity of TVI is promoted by periodic away days and joint activities and training. All of the staff teams identify the pressures of delivering a 4-tier service across a wide catchment area: the need to drive to community venues; the value attached to consistency and continuity of staff in group settings; and the employment of so many part-time staff, implies challenging logistical planning. Not all staff will therefore gain experience at all levels of the TVI continuum.

Team members tend to be of multiple professional backgrounds, and most staff have some experience (as provider or user) of mental health services, and some training (whether past or current) in a range of psychological approaches. Staff supervision and support and clinical meetings are important in TC culture (as are the separate group debriefings which take place after each group). For example, in Oxford, Wednesday afternoons are set aside for staff 'community' meetings. However, it can be difficult for part-time members to attend, and there is insufficient time to consider all the areas of general and particular practice that staff would like. Supervisory arrangements are relatively complex: in addition to line managers, staff may arrange external supervision to match their disciplinary background. Team meetings may be facilitated by an external person, to enable the team to reflect on internal dynamics. In addition, staff are encouraged to take up '"bubbling": it means being kind of paired up with someone that they can meet with for informal kind of support and supervision throughout the team, and that side of that people just naturally do anyway.'

Although staff have different training and backgrounds, most work as therapists within a group or community setting. Group therapists were asked about their role. '(The groups) follow a very structured analytical type model, so I feel quite clear why I am there: I am there to conduct the group and to keep it safe, to help people uncover things that they are learning about themselves…. As a member of the community, I help to contain and help to monitor the temperature I suppose of the room, to be mindful of people's needs, and the emotional climates if you like, the emotional temperature, but not necessarily there to dish out advice or tell people this is how we do it.' Another responded: 'You want the individuals that you are working with to find their own expertise and develop their own competencies.' Asked about the 'pitfalls' of such a role, another TC staff member said: 'I think you just have to be open about your vulnerabilities, I think rock solid is probably not ideal … just aware of what your vulnerabilities might be…. we have to constantly be self monitoring, monitoring each other so if you think you are going a bit heavy on her there, does she really annoy you? We have got to get that out of the way and keep saying you are worth working for here, we are willing to work with you, and we want to keep our commitment to them going, however hard they might try to put us off.' Yet another staff member elaborated: 'I think there is a kind of expectation or even a remit that they're all a bit 'sorted' and the TC members all aren't. I mean granted we aren't diagnosable, otherwise I hope we wouldn't be working here. But …people that need to work in this area have intense emotional needs themselves, and only by having a life outside and a way to kind of balance that can you sort of stop yourself getting sucked into PD workaholism, and it's rife …'

1.3 Client group and referral process

Applicants to TVI services are not immediately assessed by strict diagnostic criteria. However, around 80% are in contact with secondary care (CMHTs) (although 65% are self-referrals), and so far 100% are diagnosable with PD according to diagnostic measures. Applicants are encouraged to enter services through a Tier 1 or 2 route, which some staff describe as an opportunity for assessment and self-assessment, and the person's 'fit' with what the services offer. Services prefer that service users make the first contact as a sign of minimal commitment. 'We try not to put those big barriers in … to work with referrers at the first point of contact in a very informal way to assess whether it's suitable for that person, but we are finding we get pretty appropriate referrals at the moment.'

Applicants should be at least 18. People with severe mental illness, insufficient cognitive ability to contribute to the group, or substance misuse problems beyond their control would not be thought suitable for the TC, although because of the range of options available, they may be supported to enter at the Tier 1 or Tier 2 (see below) level. Most importantly, 'somebody has got to be willing to want to engage: it's not something that you can enforce. By any therapy standards you've got to want to do therapy, otherwise it's not going to work, and it's an eighteen month programme, whether it's a full time day service or the spoke, so it's a big chunk of somebody's life that they're committing.' If they do want to join the Tier 3 TC, they are required to come off medication in Aylesbury and Reading (although this can be phased), though not in Oxfordshire, 'Sometimes people are heavily medicated and diagnosed as bipolar …. you gradually take them off their medication and find magically that that's not it at all and they have been wrongly diagnosed for all those years and the medication is quite unhelpful.' The use of benzodiazepines is a particular problem: 'they blunt people's affect and other group members can't get to them…. We have been running a medication/drug policy: you halve your benzodiazepines by the time you come into therapy, alongside no illicit street drugs and no opiates. And within a few months of coming into intensive therapy, we aim to have you free of all inappropriate medication…' Another added: 'If you give patients the support and belief that they can do it; I think one is surprised at what they can manage.'

All TVI services recruit 60-70% female service users, and the largest cohort sizes are in the 36-45 age group. By this stage, most have substantial histories of contact with MH services, and the demonstration of reduction in service use has suggested significant benefits arising from engagement with dedicated services.

1.4 Model of intervention, expected outputs and outcomes

1.4.1 The TVI model

TVI is a 3 county network of services for people who have emotional or mental health difficulties – sometimes described as 'personality disorder' or 'complex needs'. Services are based on the therapeutic community model, and the philosophy that change happens in group settings. 'We fundamentally stand on the idea that the attachment must be to the group, that's where you've got to form your attachment… The group serves as some sort of transitional object whereby you can put your trust in it, and develop dependency on it and then ultimately detach from it, you know, a maturing and growing up process because you have a mirror to look in and reflect on how you are in certain situations.' The use of the term 'Tier' is specific to TVI (as is the use of the term 'spoke', which has more geographical, service user outreach connotations here, while in other pilots, it is associated with indirect service activities, such as consultation with staff of psychiatric services).

There are 4 tiers of provision in TVI: pre-therapy groups; therapy groups with accompanying support; intensive day treatment programme (Therapeutic Community) and post therapy/step down services. Tier one services are about engagement: this might involve exchange of information with an interested person in a relatively informal setting such as a café with a person who wants to find out about the services, a series of one-to-one meetings with a staff member, or a weekly group, preferably in a community setting. Tier 2 is a once or twice weekly therapeutic group, based on TC principles, possibly with complementary (or alternative) 1-2-1 therapy. The 1-2-1 approach may be needed at Tier 2 in some cases in order to bring potential members to the point of engaging with groups, or it can help retain people in groups. Tier 2 can span 18 months, includes opening and closing community meetings, and may be enough in itself for some people. 'Some of them have family commitments. They basically do 1 ½ days rather than 4 ½ days: it's a lower impact on their time, but it still is an intensive therapy.' Local audit data supports the idea of this being a stand-alone service. It shows that people in the tier 2 (2 session per week) service can have similar outcomes to those in the tier 3 (5 day intensive treatment) service. Options groups and Tier 2 have attracted more people than would want to move onto T3, so a bottleneck has developed in Buckinghamshire (although not Berkshire and Oxfordshire), with members being reluctant to move on. Engagement and retention at Tier 3 - the five-day a week intensive day therapeutic community programme - is harder than at preceding levels, and the work more intense: but staff say that it is also better contained and structured. Tier four is a post-therapy intervention which may be a group, such as the user-run STARS (Support, Training and Recovery Services), but could also involve putting people in touch with training, education or employment. Tier 4 services are the least well developed in TVI, as they are primarily for people who have completed 18 months' treatment in TC. Tier 4 concentrates on 'consolidation post-therapy, and the moving on type of scenario'. In Oxford, fortnightly sessions were planned over 16 weeks in response to user demand: however, at Tier 4 there is careful consideration of the need for the ex-member to achieve independence from the service, to demonstrate recovery. Tier 4 groups can also engage users in STARS and TRRT roles (see below).

Despite local variation in scope and stage of development, the TVI conforms to a shared model of the Therapeutic Community, although staff may also cite mentalisation-based therapy, Cognitive Analytic Therapy, Psychodynamic and Cognitive Behavioural Therapy as influencing their work.

TVI is aiming to operate a Tier 1 (Options), Tier 2 and Tier 3 (a full-time TC) in each county. This is potentially a progressive model for service users, but may also amount to a menu of alternatives. 'You can move between tiers, it's not prescriptive. We try and make it as flexible as possible to suit individual needs.' The Tier model offers choice and accessibility, and allows people the opportunity to experience the TC model, and to withdraw from drug use if that is an issue. There was some variation in use of the terminology across TVI: some respondents placed Options groups in Tier 1 and others in Tier 2. The development of these pre-TC services across the counties and the present configuration, may be slightly different according to staff and other resources: 'pre-therapy', 'therapy' and 'treatment' were also used to distinguish engagement, Tier 2 and Tier 3 services. An individual's progress between Tiers is planned: for example, in Oxford, TC members (Tier 3) attend the Tier 1 Options Group for liaison, and arrange week-long visits to the TC for a person considering advancement. If the person then decides to apply to TC for membership, s/he is invited to attend a case conference in TC to talk about themselves and the issues they want to work on with existing members. Where the TC is sufficiently confident to take on this responsibility, the TC members then vote on whether to admit the person. Respondents described some tensions voiced by TC members, and some protectionism within the TC. 'To members, it felt like a them and us, like they (the Tier 1 group members) are nothing to do with us, they come in our space, they drink our coffee, and leave a mess and all of that, and we had to try to encourage a shift in mind set around: actually these people are potential members.' Maturation of the TCs has involved the development of a sense of mutual support between the two levels, and the recognition that the TC model requires a certain number of members, and therefore additions to membership, to function. The aspirant member is also supported by the Options Group at this transitional point, and, having visited the TC and had contact with the liaison member in the Options Group, will not be entering TC as a total stranger.

Referrals to TVI services are said to be largely appropriate: and with the emphasis on motivation, self-referral to Tier 1 (from which other Tiers can be accessed) is encouraged. Assessment is a relatively informal process which can span several sessions, and details of those who are not already attached to Trust services are recorded anonymously, so as to protect people from acquiring a stigmatising label before they can benefit. Assessment is allocated to therapists involved in the services offered in particular counties, and this may involve a wait time of up to six weeks, as staff are busy servicing groups. Alongside a two-way exchange of information and options, emphasis is placed on drawing up a safety plan as part of the assessment: 'Hopefully having been enlightened by conversation in previous sessions, been made aware that they might cut or they might have a history of overdose or impulsive behaviour, the safety plan is to help people think about what will keep them safe if they are starting to feel a bit stirred up, but also because we have very often very little knowledge of that person or what triggers them or how they can behave or respond in a crisis.'

The TVI TCs are based on a structured model, with different tasks allocated temporarily to different members, and an expectation that the more mature members – 'the people who can demonstrate the model' - increasingly take on responsibilities for carrying the culture and structure, for example, by promoting the rules. There are no automatic exclusions for those who transgress after joining the service; expulsion would be avoided wherever possible as the service works to reduce exclusion. People who transgress boundaries in the groups may be suspended for a period to give them time to reflect. As far as can be managed, groups are run by the same staff through time. The experience of TVI staff parallels that of other pilot TCs: over time, progress is tangible, but there are always days when staff feel they can do nothing right. 'I think there are days when we feel we're doing a really good job and times are getting better and there are days when we feel attacked, persecuted and we feel no matter what we do is wrong and they're too nosy, too inquisitive, their expectations are too great … And I think all of us struggle with how much information we give away about ourselves.'

Intended outcomes of the TVI model are: improved coping skills, reduced suicidality and self-harm, symptom reduction (depression, anxiety, dissociation, psychotic phenomena), qualitative subjective change reported by service users, and improved relationships with other people, which are all indicators of progress toward the goal of recovery. 'We are trying to provide a service for those people that's been essentially lacking before, but it's based on a recovery model so it's not about just trying to keep people ticking over, it's actually a recovery model: we believe that that can happen for most people.' TVI Tier 3 therapeutic communities and some of the spoke services also aim to provide 24-hour crisis help by phone, involving two community members offering support to other members and to each other. Use of the service is brought back into the TC the next day, or the spoke services when they next meet. 'The out of hours support is by other members of the community, not by staff, because it has to be that you give the power to the individual back, you give them it back and you can't do that if you're the member of staff and you know best and you're going to handle it.' Coping strategies are also discussed in TC, 'to encourage people to carry on with things they've already learned and not to fall back into the unhelpful patterns.'

The TCs – or rather the TC member - within TVI take on CPA care coordination after the first three-monthly progress review. Staff do not case manage and service users are responsible for their own care planning. Tier 1 & 2 service users remain with their original care coordinator in Buckinghamshire and Berkshire; in Oxfordshire two of the tier 2 groups take over care and one (Witney) does not, and managers comment that they have to stress this with referrers. 'When somebody comes into us … into a pre-therapy group, we actually like everything else to remain the same if possible, because that then really does give people to feel that they are allowed to just come and see and dip the toe in, rather than all change and somebody discharged. If somebody then decides to move on into the treatment part of the service, they obviously have to be on CPA, they have to be on enhanced CPA, given the kind of amounts of therapy they'll be receiving. At some stage and usually around the three month time, we encourage a CPA handover to our service, and that's when we then take over full responsibility, and actually discourage any other services to be involved, so we don't want clients to be engaged with other therapy primarily - not because we're precious, but because it potentially can cause confusion to the individual.' The TVI model is consistent. Although members are not particularly happy about it, RMOs (at least in Oxford and Reading) will not sign applications for Disability Living Allowance: they expect people to move away from dependency and disability.

1.4.2 Oxfordshire Complex Needs Service

The Oxford Complex Needs Service (CNS), the largest team in TVI, was initially located in a portacabin on a hospital site, but relocated in March 2006 to new accommodation in a relatively deprived and culturally diverse part of East Oxford, close to the town centre and with excellent public transport links. Despite the single use occupancy of the building, and outdoor garden, there remain insufficient offices for staff, and insufficient space to accommodate other parts of TVI. A 4½ day Therapeutic Community Programme is run from the Oxford base, and there are Tier 1 services in Oxford, Banbury, Wallingford and Witney, and therapeutic spoke groups (Tier 2) in all these locations bar Oxford (because the main TC is available there). Options groups are supplemented by 1-2-1 contact in some, but not all, locations. Voluntary sector premises have been found for these groups, with Mind offering accommodation in some areas. The Tier 1 and 2 groups run on TC principles, but there is no necessary expectation that attendees will move on to the full TC. Service users in Tier one are, however, encouraged to move on to either Tier 2 or the full TC when it is likely to be helpful. The Tier 2 services are intended as stand alone services and aim to fulfill the needs of many individuals in their own right. The Wallingford service, for example, is organised to offer contact to members via a fortnightly individual session of 50 minutes, a weekly large group and a weekly small group session. The challenge then is to retain, develop and expand the membership while members are in the process of gaining confidence in the group. Members were sufficiently confident of the TC model to take part in the Community of Communities (Association of TCs within the RC Psych) audit cycle. TC members also provide liaison and support to Tier 1 members in Oxford, hosting 'visiting weeks' to the TC proper to enable prospective members to consider move-on.

The full-time Therapeutic Community in Oxford runs from 9.30 to 15.00 (to accommodate parents) Monday to Friday (half day on Wednesdays), and offers a range of groups (creative group, psychodrama, small groups, objectives groups and large groups) as well as cooking, shopping, eating, working and playing together. Members continue to offer telephone support to each other 'out of hours'. Membership of the TC was sufficient to support three small analytical groups by June 2006. 'The mix is important to the TC model, the mix is there because people just like you and I would respond very differently to different types of therapy, what might help you might not help me, and vice versa, so the whole idea is to have more variety, as long as they ebb and flow together, the more likely it is that you're going to access somebody with their personal therapy aims and issues, you're more likely to make those connections.'

In Oxford, the Tier 4 component works with individuals leaving Tier 2 or 3 in a planned way to help them achieve their potential via work and training. Tier 4 provides the 'moving on group', a six-month follow-up interview and a further option to participate in an ex-service user's social networking programme. The 'moving on group' is structured as a rolling programme of 8 sessions over 16 weeks which individuals begin to attend 2 months prior to their planned ending of therapy, and which continues for 2 months after their leaving date. The sessions cover areas that promote social, mental, physical and spiritual well being. The Oxford team also runs from time to time an 8 week educational/ support program for relatives and friends finished at the end of March 2006, with the option of joining a longer term support meeting fortnightly for a 2 ½ hour period. The course is well-attended, despite operating during working hours, and it is planned to make this intervention available across the three counties.

Oxfordshire illustrates the difficulties of supervising staff across different areas/activities. There have been different take-up rates in different areas, and there are differences in the format and range of services at each site. 'They all run at slightly different times, Banbury was Mondays and Thursdays, Wallingford is different days, the options group is on different times, Witney doesn't have individual sessions, and the way the groups have decided to deal with things like the CPA or how they do case conferences or reviews has also been negotiated differently.'

1.4.3 Berkshire Personality Disorder Service

Berkshire has a long-established Tier 3 non-residential therapeutic community and a Tier 2 service called 'Tuesday afternoon community' (TAC), both based at Winterbourne House in Reading. Winterbourne House has apparently been very successful with the limited number of service users who spend a substantial period on treatment, but has in the past been perceived as vulnerable to service cuts. It was part of TVI as it was the basis of the new TVI model and therefore the pilot project could both support it, and build on its experience in the TC sector, disseminated by ex-Winterbourne service users. 'They (commissioners) don't look at cost-effectiveness, they perceive it as a bit of a Rolls Royce service, very geographically based, so it doesn't really serve the whole of Berkshire, you know, it's a bit of a luxury that they can't afford. That's their perception and that's why it's constantly under threat of closure.' However, Berkshire received very little funding for additional Tier 1 and 2 services from the TVI pilot monies.

Following the appointment of a new programme director in Spring 2006, the Berkshire Personality Disorder Strategy Forum (a partnership within the Trust) was revised to reflect a membership that could take decisions regarding the implementation of a full network of PD services across the county, incorporating the Winterbourne House services. In addition to direct services for service users, professionals such as CMHT and acute staff can also apply for full psychotherapy assessments, staff supervision (within and outside the service), and support or liaison. The Strategic Forum developed six Tier 1 services (in Reading, Wokingham, Bracknell, Newbury, Slough and WAM – Windsor, Ascot & Maidenhead) in 2005-6: it was intended to develop Tier 4 services in the first 4 of these locations, and Tier 2 services in Reading and Wokingham. Reading currently hosts the Tuesday Afternoon Community (TAC) group and the Therapeutic Risk Assessment Group (TRAG) for parents struggling to manage their violent behaviour towards their children. The complexity of the spread of services necessitated the development of accessible pathways for users entering the system at any point: and this work was still in progress when we visited the service in summer 2006.

The Berkshire service is aligned with the Trust Psychotherapy Department for historical reasons, and service users referred through the single shared point of access can move on to PD tier 2 and 3 services, or to psychotherapy services. Senior staff see the TC as more accessible and safer for a wider range of service users than is psychotherapy. 'I see Psychotherapy Services and PD Services as two very separate animals and I am very keen to preserve that they have a Psychotherapy Service which has nothing to do with PD. We, of course, treat PD patients; we always have and we will always do so but it is not a specialist PD service… I think there are people you put into a TC that I wouldn't touch with a bargepole in formal psychotherapy; and I think you can also take more risks … in psychological terms. But I'd have a go, if I thought someone had some ability to use TC I'd put them in one to see: whereas in Psychotherapy I'd need to be pretty sure that they had some capability of using the model.' People can enter the PD services at any level, although they do need a professional referral at Tier 2 or 3. Tier 1 groups, called Link Groups here, are accessible through self-referral, and this is a pathway for those not engaged with services, as they can be referred into secondary care from Tier 1 in order to qualify for more intensive services.

At the point of our visit in Summer 2006, Tier 2 services were still being planned, and there was interest – in the context of using resources already available – in combining a part-time therapeutic community structure with Cognitive Analytical Therapy (CAT). Managers stressed that they did not work 'eclectically', combining convenient strands of different models: CAT was the model they had the resources to deliver without a 'patchwork' approach, and without additional funding.

A further Tier 3 service was planned for Slough, in the East of the county, to complement the Reading-based TC at Winterbourne House, and a detailed proposal for a Tier 3 personality disorder service at the Therapeutic Day Unit at Wexham Park Hospital, Slough was submitted, in partnership with South Buckinghamshire (who later withdrew). This was for county-wide referrals into a pilot DBT (Dialectical Behavioural Therapy) programme, a three day service offering 15 places for one year for service users with personality disorders. The service would liaise with other Tiers of the PD service, and link with Tier 4 as part of the disengagement process for service users. Tier 4 services were also under discussion, with use of the internet, step-down services, and opportunities for education and training being discussed in the context of a 'discharge' group in the TC. The range of services is consistent with the stated aim for Berkshire to deliver alternatives to those people not suited to the full TC option. Winterbourne managers feel they have had some success in promoting take-up within TC by people from diverse cultural backgrounds.

1.4.4 Buckinghamshire Complex Needs Service

Buckinghamshire had no dedicated PD service, and was further disadvantaged at the beginning of the pilot when funding allocated through local budgets was misdirected and delayed. Because of the small staff team, collaborative working across teams and agencies is essential. The service is again delivered in four tiers. Tier 1 is the weekly 2-hour Options Group, in High Wycombe & Aylesbury, with a further group planned for Chesham. It was noted that some of the referrals into this group (eg by Revolving Doors) concerned offenders who needed further assessment before joining open groups, and this placed demands on the limited staff team to attend case conferences and liaise with referrers. The groups were also depleted by the opening of the Therapeutic Community in Aylesbury: although move-on is clearly desirable, the pace of move-on can be threatening to the survival of the remaining group.

Tier 2 interventions in Bucks are delivered primarily through twice weekly analytic groups in Aylesbury and in High Wycombe. Service users may also work with the Psychotherapy Department in once or twice weekly heterogeneous analytic groups or in individual therapies. Additionally Tier 2 is provided by assisting mental health services to ensure treatments for this client group are co-ordinated and appropriate. The team will coordinate treatment interventions at this level for service users who have engaged, but may not be ready for, or do not require, more intensive specialist intervention. As a part of this process, meetings will be held with Day Services Managers, to support and enhance the work currently being undertaken within Day Services for this client group.

In Buckinghamshire, a three-day TC programme was delivered for up to 18 service users in Aylesbury from November 2005, starting with 16 service users. Subsequently there have been a number of drop-outs, some of whom have re-engaged in other parts of the service. In June 2006, there were 10 members in the community, visiting weeks for new members had begun to increase the numbers of service user members, and the first new member has been voted in since the community opened. Within TVI, this is the newest TC, and it therefore experiences many of the difficulties found in TCs across the pilots, including the need to reinforce boundaries around attendance. Because of the relative immaturity of the TC, Tier 4 provisions had not yet been introduced in summer 2006.

The TC model was new both to managers and service users. The Tier 2 interventions had successfully recruited about 25 service users each by November 2005 when the 3-day TC opened. The Aylesbury services run from a Centre shared by a CMHT and acute ward, which is not ideal. Initial referrals to the service were very complex, but as referrers learn about the model, complexity has declined. The system now has more capacity to work with a range of difficulties: 'We work closely with the Psychotherapy Department, so if we see somebody who is perhaps on the lighter end and is working full time, has got kids and we think, OK they could benefit from Options, but perhaps a Tier 2 Group might suit them better, we would ask Psychotherapy to see them with us, so we do joint assessments.' Run with a tiny staff team, the Bucks CNS is also trying to develop new targeted Tier 2 services concentrating on Young People (whose needs are different) and on anger management (in conjunction with Psychotherapy Dept). To supplement the staff team, they are also trying to involve the voluntary sector in joint ventures. Space remains a challenge, especially if the service is required to recruit up to 50% from a partner agency : 'Our space is going to actually stop us, because we haven't got enough space to have many more than, say 25. And we couldn't run five day a week Therapeutic Community because then we wouldn't be able to run the Options Groups…The other disadvantage to being based in a hospital, our kitchen is shared with inpatient services: we can't leave anything (food, knives) in the kitchen … so we're actually always aware that the space isn't just ours, it's other peoples' space as well, not during the days we're here, but when we're not here.' Bucks CNS has two STARS (ex-service users) who help to run the two Options groups.

The speed with which new services have been set up has made it difficult for service users and staff to settle into the model. A manager comments: 'We were pressurised a lot in setting up the TCs and I think with hindsight we'd have been a bit more careful about the members we took in initially and … because we've had quite a few drop out … we had some very damaged people that came into our TC … and they've come back, the ones that have dropped out and we leave the door open for them…. But I think everybody who's come into the TC has learned something, no matter how damaged they are.'

1.5 Indirect Service Provision

TVI is closely associated with the NIMHE training funding, which is evaluated elsewhere, so is not described here. TVI is most prominent for the use of ex-Service Users in activities such as external training and research. STARS service users (see user involvement section) are the main vehicle for this work. However, all the county staff teams, in collaboration with current and ex-service users, provide training and consultation to local services. The Thames Valley PD course is a one year, practice based course and has run for three years, and is a source of further PD Agents to extend the basic awareness cascade and service advocacy networks. Training mainstream mental health staff appears to be cost-effective, eg in reducing inpatient days:

'Someone who had been an inpatient for four years, came into the therapeutic community, needed to be admitted and she was out within two weeks because the team went in and worked with the staff on the ward and community mental health teams. When someone goes into hospital they just go, 'Oh great, not my problem any more,' and there's no continuity there's no contact, they don't try and get that person out, because generally if you've got PD and you're in an acute hospital it's going to be a bad place for you to be …. (We need to) spread that culture of letting the client have some sort of agency, have some sort of control.' Oxford staff may be called upon to help the Trust make decisions about individual cases, where the person at the centre is proving particularly expensive in use of secure bedspaces, and is perhaps unwilling to engage with treatment.

As well as a demanding schedule of planned training and consultation among statutory and voluntary sector providers, the Oxford team provides substantial informal telephone support to workers from other agencies. The focus of training is not always directly PD. A successful training day on Anti Social Behaviour Orders was facilitated for agencies in the homelessness network, in collaboration with the Elmore Team and Oxford Night shelter Resettlement Team. The Oxford team are supporting Oxford and Bucks Mental Healthcare Trust by participating in 'Better Services for People Who Self Harm Project' led by the Royal College of Psychiatrists' Centre for Quality Improvement, supporting Experts by Experience to take part in auditing of relevant services. The Oxford team is also creating links with prisons in the County, taking groupwork into the vulnerable prisoners' wing of HMP Bullingdon with Oxfordshire Mind. In a separate initiative, the team is working to develop a Tier 2 Options group at Bullingdon for 'Prolific and Priority offenders', who account for 10% of active offenders but 50% of all crime. The Oxford team is also fielding an increasing number of requests for student placements in the TC, this being an excellent means of acquiring experience and expertise both for medical training and undergraduates in mental health professions. The Oxford team offers joint placements with Mind for students at the many higher education institutions in Oxford.

In Berkshire, the PD Forum is developing a Training Centre in conjunction with Kent University and the Programme Director for the Southern Counties Psychotherapy Training (a 4-year intensive training in Psychotherapy). The partners hope to develop a formal stepped training in Personality Disorders as part of the menu of options, extending from an NVQ 3 to a Masters degree in conjunction with the academic sector.

Buckinghamshire CNS has provided training, information and consultation sessions to CMHTs and the voluntary sector; consultation to Grendon Prison; a primary care support telephone line, and staff support and development groups at inpatient ward level. Other 'indirect' initiatives include a monthly consultation service with Wokingham CMHT who currently offer Tier 2 family work to 11 families; and a series of six Transactional Analysis training sessions to both localities (CMH nurses and Care Workers).

1.6 User Involvement

The therapeutic community model involves service users in the mutual provision of therapy to each other. Democratic processes such as voting to reach decisions are a daily occurrence. The TCs also cook, cater and provide admin support for themselves. Beyond these integral involvement processes, TVI has probably done more than any other pilot to develop 'career pathways' and roles for ex-service users to conduct research, and develop and support new and user-led services. STARS - the 'Support, Training And Recovery System' (STARS) group - was developed by service users to support recovery after TC, and to promote the model, largely through presentation of their own recovery. STARS has continued to meet on a monthly basis. The STARS meeting is where all ex-service users and experts by experience come together and discuss what work they have been doing and allocate new work, such as training and presentations at conferences. It also acts as a forum for feedback on training events, sharing information, planning and offering mutual support. Staff in the teams across TVI are invited to make requests for support from STARS, for instance a STARS member responded to a request from the Oxford team to be involved in planning a course for carers; STARS help to run Options groups across the three counties. Each STARS meeting is divided between training and supervision. Some of the members are now officially employed by TVI and are involved in helping staff run Options groups, and the group fosters skills and confidence relevant to employment.

TRRT (Training, Research & Recovery Team) has a training, research & evaluation and service user involvement brief. Two ex-service users were recruited as researchers, and were tasked with ensuring that all 3 clinical teams were collecting the national evaluation data effectively and consistently, for which the authors of this report are very grateful. Another key area of their work has been to develop research into personality disorder in black and minority ethnic populations using primary care records. The research proposal was presented at the British and Irish Group for the Study of Personality Disorder in February and came 3rd in the Junior Scientist award. The researchers together with the programme manager are taking the research forward within existing resources. By June 2006, further progress had been made in developing a career pathway for service users, and a recruitment process was undertaken in February 2006 to offer clinical work and formalise some of the existing work being undertaken by ex-service users. As a result 7 new part-time posts were created in Oxford and Bucks for service users and researchers, with appropriate support and development arrangements. 'There are some service users who are self-employed on honorary contracts, but they are bound by governance and have supervision and accountability.'

'Recovery … doesn't really hit you until such time as you've left therapy and it's in the years moving on from that that actually you gain the insights. You might have gained the insights, but you put it into practice.' TVI offers safe opportunities and structures to practice.

2. Achievements and capacity of the service

The services have all recruited the required staff, opened and sustained the projected services within the pilot funding, although they are at various stages of maturity. Buckinghamshire and Berkshire are working to extend the 4-tier model, and promote accessibility of all options throughout the counties. Although TVI is of course renowned for the TC model, allegiance to the model has not prevented the development of a range of options for service users, and this may well have reduced the high drop-out rates associated with more standard TC models. (Because of the fluctuating numbers in groups, and the range of services, we have not set out any figures here: see section on quantitative data.)

Involving users in new ways as part of their 'career' pathway through services is an achievement of TVI, and there appears to be some groundbreaking work happening in outreaching prison staff and services. Some of the TCs, including Winterbourne, have also set out to demonstrate the reduction in costs – via reduction in use of other services – arising from individual engagement with the TVI services.

3. Departures from original specification: drivers & impediments

According to our understanding of this complex project, TVI have perhaps exceeded their original specification, and PD services continue to develop in the three counties. The delivery of a 3- or 4-Tier range of service options in all three counties has been ambitious. There may not be a very clear distinction between the Tier 1 and Tier 2 services. However, the activities of the Options Groups are flexible: although based on the TC model (albeit in one or two weekly sessions), attendees do not appear to feel committed to progress to that, and may consider other options both within and outside the TVI umbrella.

The greatest obstacles to development have concerned the rapid spread of the different services with limited staff resources, with coordination and supervision of staff within that context being a considerable challenge. The TC and the group models have also had to contend with the particular difficulties groups face before they become *'at ease with themselves'*, and the tendency of frustrated or scared members to challenge the boundaries set, or to leave. Because the model is progressive, but service users progress unpredictably, the systems approach is subject to 'bottlenecks', with Tier 1 and 2 groups sometimes bursting at the seams when insufficient numbers commit to the more intensive full-time TC. Other challenges arising from the range and configuration of services have involved covering of staff who have planned or unplanned absences, and the need to find premises: several of the services had temporary accommodation, and these aspects of lack of continuity has increased the difficulty of containing service users.

4. Findings from local audit and evaluation

Local data was available from the Oxfordshire and Buckinghamshire services. The Oxfordshire Complex Needs Service collected snapshot audit data in 2006. This showed that for service users who had been in the service for more than three months (a sample of 20 people), their inpatient usage had dropped by 93% since joining the service (using an annual average). It also showed that 38% of people (a sample of 100 service users) in the service no longer needed to be seen by a CMHT. GP visits also dropped by 45% after people (a sample of 13) joined the service (again on an annual average). The cost saving that this, as well as change in medication use, was estimated to represent to the NHS was £832,910 per year. This did not include other sources of cost saving such as ED visits and reduction in self-harm, and was only for the Oxfordshire part of the TVI service.

The Wallingford group also has specific audit data for those in the group (18 people) over a two year period from 2005 to 2007. This showed a reduction in: GP attendances (70%); CMHT attendance (97.6%); psychiatric admissions (97.4%); suicide attempts (100%) and self-harm (87.8%) after joining the group. Scores on the CORE rating scale also dropped significantly. There was an average drop across all domains of 78.6%, with a particularly high reduction in the risk domain of 96.6%. Cost savings to the NHS were estimated for those who have completed the group (7 people) at £52,079 in total or £7,440 per person.

In the Buckinghamshire service, an audit compared service usage for the 6 months before and after joining the service for a sample of 15 service users. This showed a reduction in service usage in the 6 months after joining. There was a 50% reduction in CMHT contacts; a 73% reduction in outpatient visits; a 83% reduction in inpatient treatment and a 92% reduction in day care use. The service plans to collect more data on a larger sample of service users. There is also anecdotal evidence from local psychiatrists that having the Complex Needs Service in place has reduced pressure on CMHT staff both through direct and indirect service provision. It is also said to have helped with earlier provision of treatment through early identification of PD. There has also been feedback that staff in the Complex Needs Service have become more responsive and supportive as the service has developed.

5. Areas for future development

Across TVI, services are developing existing and additional services. Some of the Tier 2 groups are thinking about, planning and delivering out-of-hours support (Oxford). Since the time of interviews, this has been developed for all tier 2 and 3 services in Oxford. New groups targeting young people and carers are planned, in partnership with the education sector (Bucks); engagement work will be expanded to assertively outreach potential new members (Oxford), where it is felt that 'some people out in the community that need more than basic sessions of active engagement work'; work with prisons will be expanded (Oxford, Bucks); all services want to expand the numbers in Tier 3 treatment, and Berkshire (where the only TC covers the entire borough) would like to develop accommodation not as part of the TC, but for members to use during the week to facilitate engagement with the TC. There are also moves, as elsewhere among the pilots, to develop services such as a 'long-term slow open group for these people who aren't suitable for anything but actually need continual support', that is, those who will not recover, but who can be supported to improve their quality of life. Similarly, some staff would like to see a psycho-educational, skills-based aspect to the services and this is already in place in some parts of the Oxfordshire and Berkshire programmes.

6. Summary of lessons learned by service providers

- There are challenges in supporting ex-service users in an appropriate and timely fashion, which require efficient systems for payment of expenses, supervision, career progression and personal development. The benefits of developing a good system are huge for individuals and services.

- Recruiting staff from various professional backgrounds, as well as others with no registered clinical training, and ex-service users, as in the 'Capabilities Framework', is vital in creating an accessible, affordable and effective PD service. This includes investment in training, supervision and team building and hosting student placements.

- Partnership work with the voluntary sector and others is essential and can help in addressing the issue of ensuring that people from black and minority ethnic groups and often excluded groups such as homeless people can access services.

- Audit and clinical outcome data (including health economics) demonstrating the impact of the service has proved very useful, and is best collected routinely as part of the clinical process.

7. Summary of Service Users' Views

The TVI service was treated as three separate sites for the purposes of Module 3: TVI Berkshire, TVI Buckinghamshire and TVI Oxfordshire. Across the three sites, a total of 38 people participated in interviews or focus groups, 18 in Oxfordshire, 7 in Buckinghamshire and 13 in Berkshire. In TVI Oxfordshire, interviews were conducted with eight current service users (three men and five women) and two carers; a focus group was conducted with eight current service users, all of whom were women. In TVI Berkshire, three focus groups were conducted, one of which was with past service users and the other two with current service users. In TVI Buckinghamshire, one focus group was conducted with current service users. Interviewees had been in contact with the service for between 3 months and four years; they had variously used the options groups/Tuesday afternoon community and therapeutic communities.

There were some common themes across the three sites, as well as some differences, which we have endeavoured to highlight.

Information and Assessment

The interviewees had mixed experiences with the initial information they were given about the service. Some said that they had not been given any real information about the service, its purpose or the nature of support offered. Others expressed more positive views although a few said they had needed more time to absorb the information.

Deciding to try

Many service users had neutral expectations about what the service could offer them, saying for example, that there was nothing else, it was 'the last resort' and it was hard to expect anything when you did not know anything about the service. Indeed, some felt that they had had no choice about attending the service. Concerns were expressed about the possibility of finding that the service did not suit them and ending up with no support.

Support received

(1) Preparatory groups

In common with other TC services, each of these sites has a preparatory group to prepare people for the full therapeutic community; in one it is called the TAC (or Tuesday Afternoon Community) and in the other two it is called the Options Group. There were mixed feelings about these groups, including some serious criticisms. Many people expressed concerns about the lack of time to talk or to deal with feelings in the group, which could mean that they would be left with their feelings at the end of the session or did not feel that they were making progress. They felt that there were too many people in the group for everyone to gain support. Other concerns were that the group was unhelpful or tedious, there was a lack of one-to-one support and there was no peer support phone line at this stage in the service. In one site service users were concerned about the waiting list for joining the TAC. Once people accepted a referral to the TAC some described not being able access any other forms of support while they were on the waiting list and a number said the waiting list had been up to 3 years.

Entry into the TC included an introductory visit and a case conference at which a prospective service user presented their own case to all the current members of the community. Members then voted on whether the service user could join. In one site, service users described this as '*scary & horrendous',* although one person had found the powerful experience of being accepted by their peers as being a 'turning point'.

(2) Therapeutic community

Many people were generally positive about the support they received from the service, and some were grateful for having access to the service. They mentioned such aspects as: having long term support, being able to express your feelings, a focus on underlying problems, the opportunity to think and work through problems and to do so in a safe and supportive atmosphere, to get feedback and practise new ways of behaving. In two sites the venue was described in positive terms because it was not in a hospital setting and because of its central location. In one site, there was some feeling that there was not enough time for the therapeutic community: that it was trying to cover in three days a programme that might normally take place over five days. Community members had raised this issue and staff had tried to help, but the problem was not entirely resolved.

Some service users said they would have preferred individual therapy, but had come to appreciate the benefits of group therapy over time and, on reflection, were glad they had taken part in it. Some were very positive about the benefits of group therapy, describing the mutual understanding gained from talking to others as a 'boost'. Others were less appreciative. In one site, there were mixed views about the therapeutic approach taken in the service. Strong concerns were voiced about the lack of clear guidelines as to how the therapy functioned. In particular, it was not explained to the service users that therapists would not usually make direct interventions or answer questions. This had left some feeling frustrated or, at times, stupid for asking questions which would not then be answered. However, a couple of people did appreciate the approach taken and thought it equipped them to deal with situations with no structure or guidelines.

In another site, service users positively described being watched and dissected by other members of the community: '*They help to tear you to bits and then help you to get over it'.* They said that service users 'couldn't hide' and that members were proposed for suspension if they didn't actively participate by voting on issues, which the community was discussing. (Each member of the community, including staff, has one vote. In theory this gives the service users the balance of power since there are more service users than staff).

Two people in one site were particularly critical of the service, and both were members of minority groups within the service as a whole. One was thinking of leaving, and it was acknowledged in the group that a few people had left, suggesting that the service was not right for everyone. (It was also pointed out, however, that a couple of people had said they might return when the time was right for them.) One person would have liked more help with welfare benefits, because of the potential impact on her if she stopped receiving them.

Rules and boundaries

Many people mentioned the rules-based nature of the service. The service disallows friendships with other service users outside the service, talking with staff about therapeutic issues outside of the group, and calling up the peer support line if you have self-harmed or are just about to self-harm. It requires service users to give up contact with other professionals, to come off medication and to keep clear of illicit drugs and alcohol. Some people felt under pressure to open up about issues in the Options Group in order to show that they were ready for the therapeutic community. Amongst those who mentioned these rules and conditions, the views were mixed; some thought they were helpful and some expressed reservations. In one site, concern was expressed about how rules were interpreted; it was said that they were interpreted and applied differently over time so that current service users could influence the relative rigidity of the culture. However, some people said they felt safer when the rules were applied more consistently.

Relationships with staff

Many people made positive comments about staff qualities and their helpfulness. A few people mentioned the lack of an 'us and them' atmosphere. Staff participated in community life alongside service users: playing games, cooking dinner and washing up. This enabled service users to see therapists as real human beings rather than someone obliged to be there and listen. Service users described staff as experienced. Confidence was expressed in their knowledge and the fact that they had seen group therapy work over a long period of time.

In one of the sites, a couple of people felt equally strongly that there was a real divide between staff and service users and little contact with staff. One person thought staff were quite impersonal and felt ignored; this participant believed that two young women had left because they felt bullied by staff. In addition, several people were concerned that there were not enough staff, that staff were not with them consistently or might not always communicate well with each other, because they were engaged in setting up other services.

Relationships with service users

Many service users spoke positively of contact with their fellow service users, and identified the support they received from each other as one of the major strengths of the service. They described feeling comfortable with and interacting with others, getting support in the groups, exchanging ideas, appreciating the peer support phone line, beginning to feel a part of something and feeling less isolated. A couple of people expressed regret that social contact was not allowed outside of the community. In addition, one felt there was a hierarchy between the new and more long-standing service users, and another felt that there were some people who did not want to make progress.

Some described the service as having a family or community atmosphere, with all the ups and downs of family life. They appreciated the lack of judgement, and the ideas and help that came from shared personal experience. Giving support and being trusted and accepted by others was felt to be just as therapeutic as some of the more formal therapy. One person said that her only support at the service came from other service users and a couple said that there was no substitute for personal experience.

There were times when the dynamics amongst community members were more negative however. Service users alluded to times when particular people had been ignored or victimised. Some said that mistakes had been made and that there were things that they regretted in the way that some people had been dealt with by the community. They felt that, through this and their reactions to it, they had gained a greater level of self-awareness.

Outcomes

Most people felt that they could see positive changes in themselves since joining the service. Many mentioned improvements in self-awareness and self-acceptance; they had learned to recognise, accept, tolerate and express their own emotions, needs and imperfections. One or two described gaining awareness of buried unconscious material and learning about flashbacks. Some people talked of changes in behaviour (including ceasing self-harm), and some of participating in vocational activities (for example, studying and looking for work). Many service users said that they had gained awareness and skills in the area of interpersonal relationships. Some had learned to manage anger or deal with conflict in more healthy ways and a couple talked of improved personal and family relationships.

Most people believed that it was the service that had helped them to make progress, although a few also spoke of what they had achieved through personal effort. Aspects of the service that were felt to be beneficial were consistency, safety (partly created through rules and boundaries) and reassurance from staff. Staff characteristics such as their humanity, being genuine, trustworthy, able to have a laugh were also cited as positive aspects of the community which had led to positive changes.

A few people had also experienced some difficulties with change. For example, one person felt that change was too slow, and another felt that friends and family might not like the changes in her. There were a couple of people for whom the service did not seem to be beneficial, one of whom did not feel they had gained anything from attending.

Involvement

Most of the service users across the three sites talked of being involved in the support provided, in their own care and in the day-to-day running of the community. However, at one site there were some who did not feel involved, or who felt that their say was not significant either in relation to their own care or in relation to the running of groups. None mentioned involvement in the running of the service as a whole.

In one of the three sites, service users described full involvement in all aspects of their own care and the care of others. This ranged from using their democratic vote, to vote people in or out of the community at the initial entry point, involvement in the case conference, or during the course of their 18 months there when members could put each other up for suspension or discharge if they were felt to be flouting the rules and boundaries. Service users were also involved in all aspects of the day to day running of the community such as menu planning, food shopping and cooking for meals and making decisions about community social trips. Service users said that they run the community having their own business meetings and finances, monthly progress and planning meetings. It seems likely that there was more experience of involvement at this site as it was the most well-established of the three.

Diversity

Dealing with diversity was raised as a problem at this service; service users were keen to underline that this applied to issues of first language, culture and gender as well as to race. In one site, there was some very positive feedback on this theme from some interviewees. People said, for example, that everyone was welcome, that it was fine to have more women than men, and some had received good support regarding childcare issues. One person suggested that more contact should be made with older people and people from minority ethnic groups. Several people raised the issue of needing help with gaining access to childcare and childcare costs.

The views of carers

Two carers were interviewed at one of the three sites, none at the other two. The carers had received little, if any, information about the service in advance. However, both were now attending a Carers' Group. They appreciated both the information/educational aspects of the carers' group and the mutual support, and were positive about the staff they met there. Both carers reported that they were involved in the running of the group, and had been offered the option to continue as a support group when the initial information/educational sessions had finished. Both were positive about the changes they had observed in their partners. For one in particular, the changes had affected them, too, as they now felt able to 'switch off' more. They also felt that their partner had become more receptive to their children and better able to relate to them.

It was suggested that there were some difficulties in accessing the carers' group, perhaps because some people were working or caring for others. An example given by one carer concerned their difficulties arranging and paying for childcare, which they needed in order that one partner could attend the TC and the other could continue to work.

Overview

For most service users, there were significant strengths in this service as well as some difficulties to overcome. The strengths included the peer support, and the support of the service in learning to express feelings, and work through problems in a safe and supportive atmosphere. The approach in one site was described as one of recovery or empowerment as opposed to more traditional authoritarian approaches. The support for carers was highly valued by the two carers interviewed at one site.

Difficulties focused on the Options groups and TAC, and a need for support on the 'boundaries' of the service (e.g. waiting list, transfer from TAC to TC and leaving). In addition, the service was perhaps not meeting the full variety and diversity of need, which service users bring. The two people who were least satisfied were from the more marginalised groups in the community. A general issue raised concerned resource cuts or perhaps reflected the provision of a service across three sites: staff availability was a concern raised by many. In one site there was a clear need expressed for more information and guidance about the therapeutic approach in use.

A7 Nottinghamshire Personality Disorder and Development Network

1. Description of service

1.1 Aims of pilot service [source – SLA & bid]:

To provide a managed social and health care network providing services at three levels of intensity:

At Tier 1, the service will support the wide range of agencies and services in contact with people with personality disorders; and facilitate the development of service user networks and advocacy.

At tier 2, the service will provide a range of clinical supports and therapeutic interventions, including case consultation for professionals; short term individualised and group based problem solving treatment (based on Stop & Think programme used for forensic service users); preparation for Tier 3 TC for service users (a weekly step-in group); case management for the most disordered service users.

Tier 3 will comprise a 5-day service run as a therapeutic community for 18-20 service users for 12-18 months.

1.2 Staffing the service

The Network has three staff teams:

- Advice & Information (A&I): 4 part-time Advice and Information Officers, a FTE Team Leader and a part-time coordinator.

- 'Stop & Think' has 4.4 WTE staff, headed by a clinical psychologist. The team is supplemented by volunteers (eg psychology students of Trent Clinical Psychology Training Course). Some sessions from a consultant psychiatrist are allocated to the programme to enable CPA where appropriate.

- Therapeutic Community (TC) has 2 full-time and 3 part-time nurses, a part-time consultant psychiatrist and a consultant psychotherapist (whose services are spread over the Network) recruited in December 2005. The TC was established with the locum services of a clinical consultant with expertise in TCs.

Staffing of the A&I service was initially via secondment from Nottingham advocacy voluntary sector services, to work alongside a user involvement development worker. As the role of the A&I team has developed (see below) to meet the needs of the Network as a whole, the Network planned to take on direct employment of the A&I team. Several Network team members have backgrounds in working with forensic service users, which may make them more open to working with people with a forensic history.

1.3 Client group and referral process

Nottinghamshire Personality Disorder and Development Network (NPDDN) is part of Nottinghamshire Healthcare Trust's Adult Mental Health Directorate. The Network covers all of Nottinghamshire which has a population of over one million people, so providing accessible services has been challenging. To qualify for either Tier 2 or 3 services, the therapeutic community (TC) interventions, service users are expected to meet criteria for a diagnosis of PD based on the IPDE (although the few who do not wish to comply with this assessment may be excused). People unable to participate in group work due to learning difficulty or inability to communicate (such as deafness) may be offered one-to-one sessions. There are no other firm criteria other than willingness to observe the rules. Self-referrals are accepted. Finally, 'before somebody joins the full time TC programme they must be off all their psychiatric medication, including tranquilisers and by the time they've been in the programme for three months they must also be off their anti-depressants:' people in the preparation group (MAC) are supported to reduce prior to full TC.

Until August 2006, people referred to the Network were discussed briefly by a referral panel, and then ordinarily invited to a Choices Event (an informal, drop-in session run twice-monthly in Nottingham, once monthly elsewhere), at which they could find out about the various options offered by the Network and in the surrounding area. 'The referral panel is just to see if there's anything in the referral letter that suggests that that wouldn't be the best first contact… sometimes if there's issues of risk or huge complexity or reluctance or childcare, then it may be that we would invite people for an appointment with two of the staff before inviting them to Choices.' The Network has also convened a Risk Management Panel made up of team leaders, the psychiatrist from the Therapeutic Community and support from the Forensic Team to discuss cases where there is indication of risk. Links have been made with the Community Forensic Team: 'we are looking at how we can joint manage some of the more forensic type patients.' International Personality Disorder Evaluation (IPDE) assessment follows on from Choices, and is discussed as an aid to developing a dialogue with, and engaging, the person rather than as an essential qualification for admission.

1.4 Model of intervention, expected outputs and outcomes

Guiding principles of the bid and the services include: attention to holistic need; flexibility; the need to support other services, including mental health, to support people with PD; and a focus on independence and self-responsibility within recovery. Since Summer 2005, the service is provided from attractive premises, the Mandala Centre, easily accessible from the City centre. Nottingham-based service users can access information, needs assessment, the Stop & Think programme, one-to-one or group preparation for the therapeutic community, and the TC itself. Satellite services replicating some of these functions have been developed at varying rates in Mansfield, Worksop, Retford and Newark.

The Network does not routinely take on CPA responsibilities. The Stop & Think intervention lasts 16 weeks; the three-day therapeutic community (a 12-18 month intervention) is developing a model whereby members take on responsibility for their own CPA. There is felt to be some incompatibility between TC principles and CPA, but within NHS services, it is also felt to be difficult to justify offering a Tier 3 service to someone who doesn't qualify for enhanced CPA. 'We definitely want them to be down to standard when leaving.'

There are three components to the Service:

Tier 1: Advice & Information (A&I) This part of the service has been responsible for publicising the service; delivering advocacy and advice to Network users; liaising with other organisations to increase the Network's capacity for varied support, and supporting other agencies to manage service users and to refer into the Network. The team also has responsibility for developing user involvement.

Initially, this central part of the service suffered from difficulty in marrying objectives and practice between the Network and the two different voluntary sector advocacy groups with which it worked. Partnership arrangements were uncertain, and staff engaged were unused to working with PD users, and were not ideally placed to promote and recruit for the service. 'Their job description was around networking: most of the service users don't want to access services at all.' However, this period of relative flux enabled a more coherent vision of what the A&I service could offer to emerge. Ownership and management of A&I was to pass to the Trust in Oct 2006. The full-time clinical lead for the Network was to have some input into A&I, as a number of service users may not progress beyond this level.

At the point when we visited the team (Summer 2006), it was planned that all referrals were to be held by A&I, with a view to developing Choices in a non-clinical, self-empowering context taking place via group surgeries, individual appointments and at drop-ins at various locations around the County. In the new system, potential service users would be able to attend up to 3 times, 'to give people a chance to think through a bit more about what it is they might be wanting and putting the right information forward to have contacts with all sorts of other services, voluntary and statutory sector.' The A&I service also want to see more emphasis on engagement. 'As a matter of precedent, Choices will offer a group experience, but then offer something secondary to that if people really can't handle the group.' The extension of Choices is seen as important, since the decision to engage with the either Tier 2 or 3 precipitates different pathways. Choices forums are run twice-monthly in Nottingham and monthly in Worksop and Mansfield.

In addition to Choices, the A&I team have fostered service user support groups which meet monthly in Worksop, Retford and Mansfield, prioritising locations outside the City. These groups are informal, inclusive drop-ins that have a range of different attendees: those awaiting a place on Stop & Think, those who have completed the programme, and those who recognise their own difficulties in the publicity leaflets but have not accessed other services. The team has also picked up advice work from existing clinical teams. 'We might get someone through from the TC who has shared in the community meeting that they were likely to be homeless by the end of the week: that's where A & I can then step in and signpost them, link people into relevant organisations.'

Tier 2: Stop & Think. The Stop & Think intervention was designed in response to a lack of psychological treatments for this group of service users. It is a social problem-solving approach based on the work of Thomas D'Zurilla and Arthur Nezu. The Network was, in Summer 2006, offering 16 weekly sessions (down from an original 20), with 12 of the 16 sessions taking the same format, working around problems brought by participants to the group: 'What sort of bad feelings am I having? What's my problem? What do I want? What are my options? You then pick a choice of which option you want to go with and generate what is my action plan? And then the final question the following week is how did I do?' It is a very structured approach, designed to encourage strategic reasoning and discourage impulsivity: it is 'containing'. While not designed to change an individual's personality, it proposes to teach people skills to help them deal more effectively with their problems. The NPDN team also delivers four sessions of additional skills training based on DBT theory: on mindfulness, inter-personal effectiveness, emotion regulation and distress tolerance. The programme has been thoroughly researched in the LANDSCAPED project in a forensic setting. By the end of June 2006 there were mixed-sex groups running in Nottingham, Mansfield and (lastly) Newark and Worksop, and single-sex female groups running in both the north and south of the county.

Interviewees were asked how a person naïve to all treatments would choose between Stop & Think and the TC. 'We tend to say the Stop and Think is for people who want to get on with their life now whereas the TC is for people that have reached a point in their life where they want to go back and make sense of their past.' Stop & Think also involves a collaborative assessment, using the IPDE: the IPDE has a role in setting criteria for the Stop & Think course (which has a waiting list), and is a research tool, but staff also emphasise its role as a tool of self-reflection and appraisal: 'Looking at the outcome of that assessment and then getting an opportunity to assess themselves, see if they agree with the outcome assessment. Explore the diagnosis, how they feel about the diagnosis of personality disorder…. And then we look at what problems, using the IPDE again if they need some help to focus, what problems they might want to change and work on …' All types of PD are represented: 'It can be difficult having narcissistic and histrionic people in the group, and drawing out avoidant types: but we have to manage them all.'

There are about 8 people in each group, but (given the client group), the drop-out rate can be unpredictable. The programme is subject to ongoing review: research has suggested that learning and commitment is maximised at around 16 weeks, so the 20 week duration has been reduced. To reduce waste if numbers start to dwindle, it has been decided to identify points at which a new intake can come in. This is balanced so that several new members arrive at one time. If a person misses 3 sessions, their place is reviewed. In response to feedback, the Stop & Think team now offer 3 individual sessions with a keyworker to group members, at the beginning, middle and end of the programme. There is a pattern of attendance reducing near the end of the programme. 'It's often never enough. For a lot of people we work with, endings are difficult and they've established relationships both with other group members and the facilitators.' Resourcing the programme across the different sites is problematic, as facilitation should be continuous: three staff are attached to each group in the hope that two will be available to facilitate. The team have adapted as far as they can to service user needs, and have occasionally delivered the programme in individual sessions, but 'almost everybody I've met has really had grave anxieties about going into the group', although some people 'learn a bit, but they get more out of actually being with other people. But I think when people grasp it and really try it works great, it has a great effect on people.' People may choose the Stop & Think programme because commitment is to one meeting rather than three days per week. Demand is consistently high in Nottingham, where applicants may have to wait 8 months for a place (August 2006); a waiting list is also accumulating in Mansfield and Worksop.

The willingness of the service to adapt to service user needs seems important, alongside the value attached to consistency. There have also been difficulties when CMHTs have discharged people joining the programme, despite its short duration. Workers also say that some referred service users need more individual work to enable them to access the groups, including resolution of Axis I disorders. There are logistical difficulties in running groups all around the county, and keeping in touch with rest of network is hard. There are few services to refer group members from outside the city to for further advice and support. 'At the end of the programme they meet with both facilitators … We just go through the good experiences, the bad, what they've got out of it … We've put a letter together for people who have referred them, and they get to read through that and help to put it together. And usually put a bit in about what their perspective is and really look at any other needs. And if they need referral onto elsewhere or to the TC.'

Tier 3: Therapeutic Community (TC). The therapeutic community is one of the options discussed at Choices. Once someone has been to Choices and expressed an interest, an appointment is made to see two of the TC nurses to talk a bit more about the implications of the TC, what it might mean for them: 'and also about safety issues, how they'd cope when they're at their worst because I think exploratory therapy means that you will hit your worst experience as you start to explore and uncover things…' People interested in the TC option can attend the weekly preparation group, the MAC, for a minimum of four weeks and maximum of a year. 'The preparation group, the MAC or Monday Afternoon Community, is the assessment process for us and for them: they attend for between four weeks and a year before moving into the three day community. During that time they need to come off medication but they can continue with existing mental health contact until their 3 month review. They also do the Life Questionnaire that they can have support with doing and the IPDE …' The MAC runs for two hours a week. Progression to the full TC, which operates most of the day on Monday, Wednesday and Friday (August 2006) requires another set of events. 'When they feel like they're ready and they do want to join, they arrange a visiting week and they visit the three-day programme as an observer and then if they still want to join they would book a case conference which is where they present themselves to the community and they have about 15 minutes to say… to talk about their history, their problems, their life and what they're looking for and then there's another 10 minutes to ask them any questions about what they've said … and then there's a vote where they're voted in or not.'

The initial 3 day community was developed in Nottingham City, opening in June 2005. By August 2006, another 1.5 day TC was running in Worksop. The TC development was supported by experienced consultants, members and placements at other TCs in Leicester and Birmingham. The programme involves community meetings, small psychoanalytic groups, art psychotherapy, cognitive behaviour psychotherapy and the model stresses the importance of informal time together. 'The community meetings are socio-therapy, in that they are more concerned with here and now reality, what's going on right now and what do we need to do right now, whereas the small group might be more concerned with the feelings that are stirred up and how they might understand them. So the small groups involve people reflecting on their past, their childhood, issues of abuse, issues of traumatic backgrounds that people have had. So if somebody's angry with one of the staff in the community meeting and feels that they are bullying them or being unfair then in the small group they might sort of unpick that: "I wonder why I feel such a strong reaction to this person? .. The small group has a psychotherapist and one other staff member, whereas community meetings have everybody in.'

There were only 7 members in the Nottingham TC in Summer 2006, three of whom were founder members, and the remainder having been recruited via the MAC. The service acknowledges that it is difficult for service users to move onto full TC, not least because of the time commitment, and this is creating a bottleneck, with too many MAC members (over 20 in Summer 2006) apparently 'stuck' at that tier. This means in effect that access to the MAC is subject to a waiting list, as is by extension access to the TC, despite its need for new recruits. The MAC is attended by two full-time TC members, as a means of liaising across the divide. 'The preparation group is the feeder into the TC and we have (had to) become more proactive in saying, "Come on John you've been coming now for six months. Are you planning on joining… being on the three-day programme? If not we need to look at something else because unfortunately there's people knocking on our door that want to come in … We definitely don't want to exclude anybody but it's just getting that balance right." It is also difficult to stay in the TC, which needs around 16 members to function properly. On leaving the TC, members are asked to return for a discharge meeting, and to have no contact with current members of the 3 day programme for a period of six months.

Most of the staff have no prior experience of working in a TC, but arriving at a balance of containment, honesty and professionalism is not easy. Most of the members – and the staff who have nursed in NHS settings – are accustomed to a more passive experience of services. 'Letting people find their own answers is a challenge: we have members saying things to us like, "What do you think to this? Why can't you just give us an answer?" and I say, "It's about you, it's no good me saying let's do it like this. It's about you finding yourself and you making the decisions." And it's so hard because they're used to people telling them what to do … and it is hard because there are times when I want to say, "No don't do it like that: why don't you do it like this?" but you can't it's about them having to find it for themselves and if it means that they mess up, they have to do it to find their way.' There is a weekly group in TC which uses the Stop & Think format. It is hoped that members will take on increasing responsibility for decisions such as sanctions on rule-breaking: staff try to ensure that the user vote is never outnumbered by staff.

There are parallel processes of containment between staff and user members: 'It's about knowing that these things are part of human experience, anger, frustration, fear, anxiety, it is a part of being a human being and it is okay to have them: that they're just emotions and they can't destroy you or anybody else ….. I guess we need to do that for each other as staff in order to be able to do that in a community really. "Yes you're angry with me but I'm still here," you know, "I haven't gone off sick because you shouted at me yesterday."' As is usual in TCs, all groups are followed by 15 minute staff after-groups. On TC days, the work is intense not least because it is continuous: lunch is eaten with the community. The TC team also has a one and half hour weekly clinical supervision slot: in Summer 2006, there was a lot of support for external facilitation of this group. The impression was given that this would militate against some of the hidden hierarchies of the staff: despite the 'democratic' label of the TC, it is acknowledged that staff are different from user members, and that different staff are rewarded at different levels.

One of the mechanisms of the TC is that members come to recognise their impact on others. The TC is also evolving mechanisms for crisis support: 'It's taken time to evolve, for members to trust each other to be able to access that support. We've had to … put boundaries in within telephone contact, a maximum of 15 minutes and no more and if that person that they were talking to needs to access support there's somebody else for them (to call for support) ... When the TC was quite small in numbers and there was only three of them, there was a huge pressure but we encouraged them to talk about that.' Crisis support is organised as and when needed if members feel they can offer it at specific times. The TC can also refer to the Trust Crisis Team. TC members may also offer each other support in practical areas and can access the A&I service of the Network.

Liaison between the 3 different tiers:

Because of the specificity of the three services delivered, and the pressure of demand on the Stop and Think team, team functions have remained fairly discrete. There is competition for space. Arguably, the integrity of the Network has suffered as a result, and staff have found it difficult to identify a 'common philosophy'. It is difficult to schedule a shared monthly team meeting which can be attended by those working in different services at some remove from the City; and the Network does not have a dedicated Network manager who might draw the different functions together. The Network has also found that, in the context of the huge area it covers, 'We haven't got sufficient clinical staff to do all the necessary work for people with Personality Disorder… The initial bid was very much that this is a network, we would be pulling together (as opposed to providing) all the services.' Resources (clinical and staff numbers) may also appear to be concentrated in Tier 3, while Tier 1, advice and information, may see more service users. Interestingly, one staff member suggested that the equality of the staff teams fosters tension between them.

However, with A&I taking on all referrals, and the TC using Stop & Think models, there are indications that 'Our differences could become our strengths'. Self-help groups facilitated by A&I and open to different service users at different stages may also help to integrate the service. The take-up by service users of the two therapeutic interventions is partly premised on misconceptions about timing, and may reduce if people are better informed at the beginning. 'People would hear about the Stop and Think programme. We'd say they could be in the preparation group between four weeks and a year and then come into the TC which is an eighteen month programme, all group work. Then they'd hear about the Stop and Think programme which was a 20-week programme that also involved individual work. A lot of them saw it as a quick fix. It seemed easier to access the Stop and Think group.'

1.5 Indirect Service Provision

Nottingham has an active third sector, and A&I have been responsible for liaising with teams offering a wide range of services (eating disorders, crisis resolution, probation, ethnic minority organisations, etc) throughout the county, building capacity within the Network and offering specialist support. Over the year to June 2006, the Stop &Think team had been involved in presenting the model at a number of conferences and seminars directed at the police and health partnership, primary care and women's mental health group, and contributed to the Leicester University Postgraduate Drug & Alcohol Course. In addition the team have delivered a number of presentations on raising basics awareness in working with personality disorder. The team does not have sufficient spare capacity to train other professionals in Stop & Think model: but some staff feel this would be a worthwhile alternative use of time. Feedback from statutory sector providers around Nottingham suggests that there is a demand both for higher level training on PD (beyond basic awareness), and for specialist consultancy support to assess and devise plans for working with service users. The Network does not have enough capacity to offer that consultative working arrangement. The Network as a whole has developed a training strategy to deliver training in PD at different levels of complexity: from basic awareness for staff coming into contact with people with PD, through those in Mental Health with substantial contact, through to the development of specialist workers. Time commitment and levels of accreditation will increase with specialism. The ability to implement the strategy is driven by resources.

1.6 User Involvement

Nottinghamshire has a strong Service User network through Nottingham Advocacy Group, Advocacy Alliance, and Central Nottinghamshire & Newark MIND. Nottingham Advocacy Group & Experts by Experience Ltd contributed to the pilot bid. Within the Network, and the host Trust, experience of service use is one qualification for employment in mental health care. Service users have been involved in quality assurance of the Network services, and specifically in researching into advocacy needs and models at Tier 1. TC members took part in the Community of Communities peer audit process, in local training of various staff groups about PD including (psychiatry and probation), and in service development (in Norwich and Oxford, through collaboration with another of the community PD Pilots, the Thames Valley Initiative). Service users have been involved in all interviews for staff for the service. Although democratic principles are at the heart of the TC model, the development of a community has required active input from members: 'because it's a new service and yes you take bits from other TCs but we've started with our own rules: we've gone through each one and discussed it with members.' A colleague added: 'It takes time for the community members to be able to accept that staff can't outvote you on most things unless it's a serious issue or something quite dangerous … this is a democracy and I think people need support in being able to challenge staff.'

The A&I team have first responsibility for promoting UI, have taken the lead in educating people about their opportunities for involvement, and supported the establishment of monthly self-help groups. There is an acknowledged tension between service user-initiated groups, and the remit of the group-based services to support and contain: it is feared that giving groups which have no staff governance (eg that deriving from the previous Stop & Think initiative in Mansfield) use of the Network logo may be misleading. The A&I team is committed to getting SU feedback on services. There are issues around carers' needs that A&I would also like to address, although all too often, it is said, the main demand of carers is that SUs access services that they themselves do not want. However, there is an identified need for carer training on consistency and boundaries, how to manage and how to live with self harm, etc.

2. Achievements and capacity of the service

Up to June 2006, the Stop & Think programme had received 161 referrals. Of these 28 were being assessed, 41 were in the early stages of treatment which included psycho-education or awaiting the start of a group and 30 were engaged in treatment (24 in group treatment and 6 receiving individual input). 20 service users had graduated from the programme. (The programme was delivered from April 2005.) The TC had developed as a culture, but needed to recruit more members to function effectively.

Some strengths of the Network were its ability to review and adapt services to reflect demand (eg the TC preparation and self-help groups; the introduction of individual sessions to Stop & Think); the scope of geographical coverage; and willingness to work with people with offending histories.

3. Departures from original specification: drivers & impediments

The ambitious nature of the original bid – to provide a comprehensive network of services across a huge geographical area – has been hampered by an underestimate of staff needed to deliver, and by mismatch with demand. The Network has not had the capacity to offer case management for complex cases, nor any continuity of case consultation for professionals managing complex cases. It has been difficult to implement a wider training strategy across the area with a shortage of staff free to deliver it (or to raise funds for additional staff). The Network has, in the opinion of some staff, had less support in terms of seconded manpower than might have been the case, and the activities have therefore been restricted to what can be done by existing staff. 'We're a three-in-one service and we're meant to be a network. It's isn't meant to be a service, a network is meant to be a connecting up of things and someone to do that work and oversee that work.' It may be that the Network needs more management and admin capacity dedicated only to building up the Network than it currently has. In terms of its proposed service user-centred outcomes (reduction in hospital admissions; engagement in training and employment, etc), the Network does have dedicated research resources, and should be able to deliver data in due course.

The specification anticipated demand at all 3 tiers of the service, but until services became available, it was unclear whether the projection was accurate. The refurbishment of premises delayed service start-up. The diversion of further resources to Tier 1 (advice and self-help), may help address demand issues. Tier 2 (Stop & Think; MAC) is overstretched and the development of the day TC slower than originally anticipated.

4. Findings from local audit and evaluation

The Network has collected information from service users on their satisfaction with the service provided. The level of satisfaction was measured on 9 items, looking at areas such as feeling understood by staff, feeling involved in treatment planning and feeling satisfied with the amount of help received. 37 out of the first 40 responses (93%) were felt pleased with the care received by the Network and 28 out of 40 (70%) felt they had been helped to deal more effectively with their problems. Positive results were also found on other items. They also have comparison data on the level of satisfaction for service users of the services they were using in the 6 months prior to using the Network. There was an improvement in the level of service user satisfaction on all items. This improvement in satisfaction was statistically significant for 6 out of the 9 items. The early results are encouraging, but there may be bias in the service users who are available and willing to complete follow up questionnaires. There may also be some bias in retrospectively rating satisfaction of another service when already linked with the Network.

5. Areas for future development

In June 2006, it was intended that A&I would develop further as the gateway for all referrals; and develop drop-ins in Nottingham and Newark. The psychologist-led Stop & Think team were planning to introduce a Schema-Focussed Therapy group, running for up to 40 weeks, as an intervention for Stop & Think graduates with complex problems who clearly need further support. There remained capacity issues, because the imagery used in SFT does not facilitate group work, and so any group run along these lines would need to be supplemented by individual sessions. It is also recognised that there is a cohort of service users who are unable to take part in group work, or require more than the Stop & Think programme can provide. Some staff would like service users to have access to individual psychotherapy (for which there is a long waiting list in Nottingham): counselling is inadequate for those with the most complex and persistent problems. There was also concern for the small staff team of Stop & Think: can they carry on delivering this demanding programme across several sites indefinitely?

Other staff have suggested it would be useful to have a community team, modelled on a CMHT, for holding potential service users until they are ready to take up Network treatments: 'We've got some very good relationships and some more difficult ones but they've got their own huge pressures … if we could have our own community team who could pick up the people who aren't ready yet, because these examples will just get bigger …some kind of community team with a sort of generic role: it might be about engagement, it might be about support in crises before people are actually in the TC'. Other staff would like more time to liaise with other providers, to support and provide case consultation, so as to have a bigger impact on the way the wider system manages people with PD. Developing the common referral pathway within A&I was generally perceived as having the potential to put more resources into engagement over a longer period, and thus to enable more people to access services, and a mechanism for regulating demand.

6. Summary of lessons learned by service providers

- Service users, particularly those with a forensic history, may continue to be excluded by PD services. Generally, community forensic services don't see it as part of their remit to treat personality disorder. So to prevent these particular service users from being excluded, resources will need to be identified to treat them separately or possibly alongside a forensic service.

- Providing a service to the entire county, has really stretched the limited staff resources and challenged the service to deliver treatment interventions across such a large geographical area. On reflection it may have been more realistic to confine the pilot to a part of the county.

- Due to the limited staff resources and the large geographical area, the service is a group treatment only and this can exclude users who are unable to cope with the anxiety of being in a group treatment programme. Whilst a group-based approach may be more cost effective it is not suitable for all those with PD.
- The employment of a Project Manager from the outset can speed up the development and delivery of a new service.

7. A Summary of Service Users' Views

Ten service users at the Nottinghamshire Personality Disorder and Development Network were interviewed. Eight of these interviewees were current service users (three men and five women) and two were past service users (both women). Interviewees had been in contact with the service for between two and 13 months. Some current service users were using the therapeutic community and others were using the therapeutic community preparation group. Both of the past service users interviewed had attended the Stop and Think group. Recruitment and interview scheduling was arranged by the service itself using the research flyers and sampling strategy.

It is important to note that our interviews were influenced by a recent violent incident in the MAC (Monday Afternoon Community) group; some interviewees felt that staff had not intervened to prevent it from happening. The effect of this incident on members is reflected in the comments to follow.

Assessment process

Most of the service users were highly critical of the assessment process; they described their experience of completing the Life Questionnaire as difficult: 'horrendous', 'traumatic' or 'intrusive'. A couple of people said they had burnt or ripped up this questionnaire on a number of occasions, whilst others said the questionnaire had a negative impact upon the family members who had supported them in completing it. It was suggested that the service should provide more support during the assessment process. There was some evidence that this might be changing, as two people said they were able to complete assessment questionnaires alongside staff.

Relationships with staff

For both the current and past service users interviewed, a significant positive aspect of the service was the staff. They were described as 'real' people, who were open, honest and approachable and who would make time to listen to the service user's point of view. They felt that the staff saw them as 'whole people' rather than focussing only on the negative aspects of their character. There was a genuine fondness and appreciation of the staff. Many of the service users mentioned the sense of equality between staff and service users within the service, that there was little distinction made between them on a day to day basis. However, at the time of the interviews, some people's feelings and views about staff had been damaged by the recent violent incident that occurred between two service users in the MAC. A couple of interviewees were angry that staff had not intervened in this incident; it had reduced their trust in staff and affected how safe they felt in the service as a whole. It was suggested that staff need to be more aware of the cliques within the service and more willing to act upon underlying friction between service users.

Relationships with other service users

Both the current and past service users described positive relationships with their fellow service users. These were seen as genuine relationships, which had positive outcomes of making them feel supported and cared for and encouraging them to attend meetings. In addition some felt the benefits of feeling they had helped others. A couple of people talked fondly of a group social outing and said they would welcome more social events and activities to help reduce feelings of loneliness. However, a negative aspect of these supportive relationships was that some said they worried about other people's welfare.

Size of groups

Interviewees from both the MAC and the TC felt that the size of groups significantly influenced their relationships with other service users and the support of the service. At the time of the interviews, there were approximately 19 service users in the MAC and most felt that this group was too large for everyone to participate in. In contrast, there were four service users in the TC at the time of the interviews, and these interviewees felt that a larger community would be more beneficial. They felt that it was harder to access inter-member support when the community was small, and there was a tendency for friction between members of the group to be more noticeable.

Crisis response/out of hours support

Although some interviewees reported that other people contacted the service when in crisis, none said that they would do so themselves. Instead they would call on a range of outside supports and phone lines. No out of hours support was made available by the service, although TC members were able to access an inter-member support network, which enabled them to text or telephone each other should they need to speak to someone outside of office hours. A similar text support network for the MAC had been terminated after the aforementioned violent incident. As a result, at the time of the interviews, there was no out of hours support network for the MAC, which was a source of concern to some of the members.

Outcomes

All eight current service users discussed some positive outcomes as a consequence of attending this service. These included emotional changes, such as an increase in confidence and a reduction in anxiety, as well as behavioural changes such as reducing or stopping self-harming behaviour and being able to leave the house more often. However, all of these individuals had also experienced some negative outcomes as a consequence of attending this service. Many of these were associated with the violent incident, which had reduced some individuals' confidence in the staff and had led to some people feeling unsafe. In addition, a number of people found it tiring attending the service and some felt they were taking on other people's problems, which could be difficult to cope with when they were on their own.

Medication policy

A key concern for most service users was the service policy on medication, which states that people must stop taking medication within three months of joining the TC. Many people said that the prospect of coming off medication was worrying. The violent incident seemed to have had an impact on their opinions, in that a couple of the interviewees reported having personal problems with aggression. They were concerned that if they stopped taking their medication, they too could behave aggressively and be discharged from the service with no other support networks in place. It was suggested that staff could be more flexible about this policy and should research the possible consequences of coming off medication more thoroughly.

Comparison with other services

Overall, most of the service users felt that this service compared favourably to their experiences of other mental health services; staff were seen as more committed, supportive and understanding than in any other service. Another important factor was the sense of belonging service users felt from being around a group of people with similar problems. Others said that sharing problems and experiences within the group was beneficial and made them feel they were not alone with their difficulties. Where the service compared unfavourably, the main reason was that interviewees felt unsafe in the building due to the violent incident that occurred shortly before the interviews took place.

Endings

An important concern for the past service users was that they felt they had had no involvement in the decisions made to end the Stop and Think group and, latterly, the graduate group. Consequently, they felt the service should have a more structured approach to ending groups and that service users who have completed their treatment programmes should be able to retain some link with the service and/or the service users.

A8 The Olive Tree Service (Coventry)

1. Description of Service

1.1 Aims of pilot service [source –SLA]:

The aims of the service are:

- To provide a range of evidence-based interventions that will significantly improve the psychological health and social care outcomes of people with personality disorder;

- To increase the capacity of staff within a number of organisations so that they are better able to recognise, manage and address the needs of people with personality disorders;

- To establish a comprehensive service for people with a personality disorder in Coventry, based on:
  - community based outreach services almost always combined with
  - intensive group therapy and
  - an education and skills facilitation team to train and advise stakeholders and address issues of social inclusion.

1.2 Staffing the service

Recruitment of appropriate staff was difficult in Coventry, and the full complement were not in post until June 2006: a team leader and 4.8 group therapists; a team leader and 6 therapists for the Community Therapy team; 2 skills facilitators and 3 secretaries. There was no free pool of qualified staff in Coventry with the right skills and experience, so staff were recruited for personal qualities such as enthusiasm, commitment, and ability to be team players. As with many of the other services, the model for the service – and job content – tended to evolve as it was put into practice: as in other pilot services, some staff went through a phase of initial misunderstanding about their roles, based on ideals of being psychotherapists in the traditional sense and accepting other complementary roles such as outreach work, flexibility of approach, advocacy, liaison and CPA.

'We had 128 people apply for 3 posts to be psychotherapists because they want to be 'the psychotherapist'. They're actually community workers who work psychotherapeutically….'. Rather than one-to-one psychotherapy, the service requires a much wider and more flexible holistic, problem-solving therapeutic brief (which is likely to develop into care coordination under CPA). Professional backgrounds are a good basis. However to work with this service user group they need to be augmented with a range of skills as the model of therapy combines psychiatry, psychology, psychotherapy and social work skills. Some of the staff recruited had been accustomed to seeing PD service users once or twice a week in sessional work: they may now spend up to 22 hours in one week with such service users, Part of the training was helping people to adjust to a more intensive way of working. Most service users are currently co-worked with other MH services. There has been special consideration to the accumulative effect of delivery intensive therapy and staff's need for reflective space to recover from it.

Supervision of team(s) and managers has developed over time, due to its complex nature, and is currently felt by the service to be consolidated. This required the development of adequate communication and supervision systems for staff which has proved to both be necessary and time-consuming. Staff are said to want tight control, clear boundaries, clear aims and clear messages (reflecting what is also important for service users). They must be prepared to share information about the service users and their own reactions to service users. The structure includes a daily early morning 30 minute team debriefing meeting. There are weekly management meetings, up to 3 hours of group supervision, individual supervision as required and a monthly staff sensitivity group, which is externally facilitated. The format of this last meeting has been controversial amongst all staff though all agree on the need for it. The format is under discussion as at January 2007. Senior staff stated that containing service users' risk, staff anxieties and keeping staff united has needed consistent input. The challenge of this containment is that different professional backgrounds are more used than others to open up, to supervision needs, sharing in groups with their colleagues and negotiating reasonable levels of personal exposure in the process. Managers reflected that those who most need to disclose and reflect on uncertainty are often the most resistant to it. An important aspect of team development is the need to establish levels, content and language for communication which meets the needs of the service users and the model of therapy.

Having different functions within the team has meant that splitting has inevitably happened and there is a need for the team to continually address these issues. There has been some refining and overlapping of core tasks across different teams (which is also a strategy for reducing the potential for staff splits along team divisions): group therapists may also deliver one-to-one therapy; and the community team is both assessing people for the service, offering one-to-one support, and preparing service users for group therapy while occasionally supporting groups.

Staff reported that a flexible approach needs to be taken with service users that include a variety of potential interventions. In order to achieve this staff had undertaken a wide range of training encompassing different therapeutic schools and modalities. For example, several staff were undertaking a course in Integrative Group Analysis, counselling and CBT and have attended evidence-based seminars, for example around DSH, DBT and anger management.

Staff of this service include two psychiatrists, specialised in psychotherapy. In addition to facilitating review of therapy, they also review medication, and the eventual implementation of full CPA processes. This has been felt by staff to be important to the service in establishing credibility among senior clinicians of the Trust within which the service is embedded, particularly when advocating for the service user.

1.3 Client group and referral process

The Olive Tree is a tertiary service, so referrals are made by existing MH services and potential service users must have an RMO. The operational manager estimates that over 80% of referrals are assessed, and out of those who complete assessment 80% of these offered a service. The written criteria for assessment and therapy include: a diagnosis of personality disorder(s); ownership of the problems by the service user; motivation to enter into treatment and to change; some capacity for psychological mindedness and tolerance for difficult feelings arising from therapy. Ideally referred service users should have experienced at least one early attachment lasting at least 6 months (because absence of such may place the person outside the reach of this type of therapy). Applicants who are heavily dependent on drugs and alcohol, psychotic or psychopathic are not accepted into the service

Assessments are mostly undertaken by two therapists, one of which is always a highly experienced member of the team. 'Assessment should convey the spirit of the unit, certainly should convey a set of principles. Clients should have some idea of reflection, recovery, ability to link actions and consequences – ways of relating, ways of exploring things. What the treatment involves, individual and group therapy, should convey a way of relating, a way of exploring things. When we have to tell people they are not suited, they should know why.' Those deemed unsuitable for the service following assessment are given an explanation as to why, what they may need to do if they are going for a re-referral or other alternatives are suggested. Assessment is collaborative and takes into account both evaluations by therapist and service user of the service users' appropriateness and readiness for therapy. Staff say that it is felt by both parties that the assessment process is therapeutic in itself. One staff member suggested honesty was a primary value for staff seeking to engage users, particularly in disclaiming the ability to offer any guarantees; plus the importance of not trying to 'make it better', a false optimism that impedes honesty, forces both parties into false modes of reassurance and downplays the trauma experienced by the service user. 'I can't stop you self harming, I can't stop the feelings, the desolate feelings, but I'm here, you know. But it's almost an acceptance. I think sometimes people are just so relieved that somebody believes that it is that desolate.' Initially it was recognised that some service users were not ready to take part in therapy groups directly, therefore a short term (7 week) engagement group was planned in May 2006 to add a new dimension to the continuing assessment. Subsequently this practice has been consolidated as routine where almost every service user goes through this preparation and it is redefined as treatment in itself. Originally the majority of referrals tended to be individuals who had a long history of contact with mental health services. Increasingly the service aims to intervene at an earlier point. The aim is to move through the continuum of ingrained involvement with services through to an earlier intervention to avoid stigma, unnecessary suffering for the service users and a waste of resources.

1.4 Model of intervention, expected outputs and outcomes

The Olive Tree PD Service is a 3-tiered service, originally nested within Coventry PCT. Since October 2006 it has been part of the Coventry and Warwickshire NHS Partnership Trust (which covers mental health, learning difficulties and substance misuse). All service users offered a service have a named key worker from the Community Therapy Team, who negotiates an individual care plan, assesses and monitors risk and works to engage the service user both in individual and group therapy. Caseload size for a full-time key worker is 10. The majority of service users are expected to join one or two groups delivered by the Group Therapy team. Most one-to-one work is delivered by community therapists and its intensity is flexibly tailored to their needs over time. Individual work with service users is creative and holistic, ranging from psychiatry and psychotherapy to social and practical aspects 'both the practical and the therapeutic'. 'The Skills Facilitation team work primarily with local providers, offering training and case consultation, and raising awareness of the service, both to improve practice and encourage appropriate referrals.

Attachment theory is one central tenet of therapy: 'If you can establish a new, healthier attachment relationship, particularly if you encourage the client to reflect on the attachment relationship, then that's a restorative experience, they learn from it, they learn to think differently about themselves and others.' Some of those taken on by the team have high levels of self-harm. For many service users self-harm persists and some staff may struggle with feeling that they have direct responsibility for reducing or stopping this behaviour. These feelings need to be explored and contained in order to avoid a position of defensive detachment from the service user's self-harm, 'if you manage risk assessment only by telling people how risky they are you shut down all possibilities of recovery.'

The service operates 9am-5pm Monday-Friday with some flexibility at the end of the day which includes individual and group work for people in full time employment. Out-of-hours crisis and emergencies are managed by the crisis team (operating in the same building) through a shared protocol. 'It seemed as if we were using the crisis team a lot in the early days, but already we - I think we're much more confident about how to manage in out of hours situations'. Crisis management strategies are built into care plans helping the service user to recognise relapse signatures and manage their crisis. Risk management focuses on understanding the meaning of risky behaviour to those who do it. Senior staff feel that clear clinical structure and defined roles are important to manage and contain risk and provide accountability. 'Containment is relevant to staff as much as patients… and they need to make sense of what is going on with patients, but more importantly, what is going on with themselves.'

The models of therapy in use are fairly broad, and staff – from different backgrounds – have found it challenging to implement. Group, clinical and individual supervision is critically important here in order to support staff to provide containment for service users. Some of the staff have found it difficult to share and interrogate experience, while at the same time transcending previous professional expertise. 'I've obviously learned a lot from the supervision here, I think the whole supervision process is contained in a psychodynamic theory, but we do all come from different backgrounds, and I think it's about that ability to be flexible, but I think that's scary at first. I really struggled for the first few months because I thought I can't offer CBT work because I'm not trained in that, I wouldn't know what I was doing, but …I've found that the way I work has been supported.' For some staff, despite the challenges, a new model of working that uses all their talents has emerged: 'For me it feels as though everything I've done to this point, kind of consolidated in coming to this unit.'

Underpinning the complex model of therapy is a strong emphasis on values and principles of the recovery ethos, identifying and developing 'whatever people need to live their life'. Goals for therapy are agreed with the service user and written down in the form of a contract and reviewed 6-monthly. These values include accepting personal experiences, maximising the potential of the person, enabling the person to react/cope with traumatic sequelae from the past, enhancing a long term perspective of their lives by reinterpreting life events and offering hope. Interactive group work allows participants to discover and develop their own identity and patterns of relationships. The aim is to bring all service users into group work eventually, so the range of groups is evolving to suit the different service user capacities. Several engagement groups (with 8 service users each) are now provided. There is a weekly 'holding' group for people who are very vulnerable with a set theme and a more dynamic group without an agenda for those who are more relaxed in group contexts. There is a variety of other groups from supportive to explorative. There is also a range of settings for instance a mother and baby group has been established, using nursery facilities. There is a Stop and Think group (problem solving) that has been running on the wards and a loss and bereavement group in The Olive Tree.

The service has established regular care planning and review structures to fit with local CPA practice. The service shares responsibility for CPA with local mental health teams. When the person has been stable and engaged for a continuous period of 6 months, full responsibility is transferred to the service. A person who continues to need many admissions may remain attached to a CMHT.

Service users are made aware from the beginning of contact that information is shared throughout the team. The service envisages the development of a more predictable structure and timeframe within the pathway, so that service users entering would know that they would spend perhaps 18 months in therapy, moving from assessment to group work, with a timetable for reviews and discharge.

1.5 Indirect service provision

Two Skills Facilitators work primarily with local staff to improve awareness and management of PD service users. Staff groups include mental health professionals, other health professionals, housing officers, police, benefits officers, paramedics. The skills facilitators also work with voluntary organisations including those serving Black and Minority Ethnic communities, user led providers and service user groups. They also coordinate user involvement in service development meetings, clinical governance, staff training and recruitment through service user forums. A job description is also being developed for a service user to join the staff, which is planned to be advertised in February 2007. Skills Facilitators have made good relationships with local services, and conducted training and case conferences with staff of the inpatient unit. Guidance for management of inpatients with PD was being developed (May 2006). 'One of the learning points is here: if you work alongside the staff, the staff will be open to training and liaison, so it's an opportunity. I tried to train people before, but they weren't interested: having education and skill facilitation resource has opened them up. I am really pleased and impressed: we not only teach what should happen, but we also provide it, and that's been a big bonus.'

2. Achievements and capacity of service

Despite initial difficulties, recruitment has been completed (33% by January 2005, 66% by October 2005, 100% by September 2006). Staff also consider the in house training to be an achievement carried out across 2005 /2006, which is a mixture of external and internal CPD. The Operational Manager noted that only one staff member had left during the first year; low staff turnover is also considered an achievement of the service. Staff report that there are also high levels of retention for service users in therapy and no serious untoward incidences have occurred. The service is fully integrated with and accepted by other mental health services. Consultation and advice around service development is being requested from the service at a regional level.

The service was originally designed to work with 26 users. This was expanded in May 2006, to 48 people and in Jan 2007 there were 25 people in the assessment process, 64 people in full service (groups and individuals) and 30 in group only activity (loss and bereavement and evening groups).

3. Departures from original specification: drivers & impediments

A key difference from the original plan was that staff found that at the time of the initial assessment some service users cannot, or may never be able to, take part in therapy groups. As a result service users can now have individual therapy, but may be involved with other types of group such as mindfulness, creative writing, problem solving and so on. Also in the original bid, it was intended that people would have intensive therapy eg 3 or 4 groups per week. "Patients have been telling us that this is too much for them. Now, clients attend no more than two therapy groups per week. One to one therapy could be running alongside, up to two or three times per week depending on need."

Original plans for service user involvement also had to be modified. Initially, it was difficult to interest service users except in the course of their work on themselves. 'I don't think we've lost a lot of people in terms of them feeling they couldn't engage with us … We're talking all the time to people about we are an evolving service and we really need you to help us.' This led to the establishment of a service user forum, service user newsletter and links to Coventry SU reference group. A carers' forum has also been established.

The service is now providing groups for a number of people who do not have a community key worker with the Olive Tree. This is a deviation from the original specification, where it was thought that all service users would have key worker.

4. Findings from local audit and evaluation

Senior management report that there has been a significant impact on the workload of other services. Examples are reduction in the use of A&E and inpatient bed usage as evaluated locally in conjunction with the individual measure of progress for service users through rating scales.

Analysis of 86 service users who have used the service examines the use of a range of services over the period of two years prior to assessment and two years following assessment. The service use data looked at A&E visits, inpatient days, outpatient visits, CMHT contacts, Crisis Resolution and Home Treatment Team contacts and day hospital visits. Using an average service usage per service user per quarter, this data showed significant impact on service use across all of these areas. In all these areas, there appeared to be a peak of service usage just before the first assessment. Usage of A&E, CMHT, outpatient visits and CRHT contacts appears to remain at existing levels until 1 year to 18 months into therapy. At this point the decline is significant in all areas and reduces to low levels. For inpatient stay and day hospital visits, this decline is far quicker, with no service users returning to the day hospital following their engagement with the Olive Tree.

5 Areas for future development

In October 2006, as a result of "Commissioning a Patient-led NHS", and changes within Coventry PCT, mental health services in Coventry along with learning difficulties and substance misuse have merged with their colleagues in Rugby, North Warwickshire and South Warwickshire to form the Coventry and Warwickshire NHS Partnership Trust. Although services will continue to be commissioned for the local population, it is not yet known whether the Olive Tree will be further developed to work across North and South Warwickshire. Senior staff report having had good working relationships with their original commissioners and the impact of changes to local commissioning arrangements presently unclear

The service has increasingly taken on CPA responsibilities, which is likely to change its local profile. Some staff members, however, feel that this may impact on the collaborative nature of the work that they do. While they can see the value of coordinated care there is a concern that this may make the service more associated with mainstream psychiatric services, which are sometimes perceived as being coercive.

At the moment, there are big differences in the amount of 1 to 1 time that therapists offer service users. This may limit the capacity of the service to deliver other service aims, and staff feel that further work needs to be put into developing clearer limits and expectations about the amount of individual work that can be offered 'We need to convey more strongly that therapists don't have unlimited resources … We need to be tougher with our boundaries.' Work is being undertaken to review the capacity of community therapists using a tool devised by NIMHE.

6. Summary of lessons learned by service providers

- In most parts of the country there is no PD workforce you can draw upon when developing a new service; you have to train your own staff. This may mean both helping existing case managers develop psychotherapy skills and ensuring that existing therapists are able to provide case management.

- Thorough assessments can be therapeutic and support the process of engaging people with the service

- Not all clients can use group work, and those that can may find intensive therapy (e.g. more than two or three groups per week) too much.

- Dedicated services for people with PD need to combine delivery of psychological interventions with social care and skills training.

- In the absence of a local service users' movement, active service users from other local groups can help kick-start the process and develop a culture of involvement of people with PD in the development of the service.

7. A Summary of Service Users' Views

Eight people linked to The Olive Tree in Coventry were interviewed, seven current service users (one man and six women) and one carer. Two of the current service users also participated in a small focus group. Interviewees had been in contact with the service for between four and 10 months and had used both groups and individual therapy. Staff at the service recruited and arranged interviews with research participants according to the agreed sampling frame.

Information and coming in to the service

Most of the service users had been referred to the Olive Tree by a psychiatrist at a local mental health resource centre. Many were told very little information by the referrer other than it was a new service for people with complex needs or personality disorder. The service users felt that the referrer knew very little about the service and that they had to wait until they had attended the initial assessment in order to find out more. Making the decision to try the Olive Tree was often due to lack of choice or a sense of complete desperation and lack of hope described by the majority of service users: 'It's a sense of "this or nothing"'. The fact that the Olive Tree was a specialist service was mentioned by a number of service users as a reason for their decision to try it. However, it also meant that some felt very anxious and fearful about being rejected and having nothing to fall back on.

Assessment

All service users experienced the same assessment process which consisted of three two-hour long sessions, two of which were interviews and one of which was a computer exercise. The process itself took six to eight weeks from having the interviews to hearing whether they had been accepted. Only one service user felt the assessment process was a positive experience; other emotions discussed by the service users included feeling traumatised, upset and distressed, although a couple did accept that it needed to be in-depth and detailed. Several of the service users said they had no external support whilst undergoing this process, and said they would have liked more support during the assessment process.

Diagnosis

The diagnosis of personality disorder and people's feelings about it featured heavily in these interviews. Only three service users had been given a diagnosis of personality disorder; the majority had drawn their own conclusions or seen it in their notes since attending the Olive Tree. Feelings about the diagnosis were mixed and included being upset, angry and frustrated, relief and disbelief. Several people felt that it was unfair to be labelled with a derogatory term when the disorder you have developed is due to abuse at the hands of others. However on the positive side, for some, having the diagnosis or being identified as having personality disorder symptoms, had meant that at last they were in a service specifically aimed at helping them. Many appreciated being in a service for others with similar issues and problems, as it allowed them to understand and relate to each other and understand the reasons behind the disorder. It also enabled them to move on and learn to cope better.

Support offered

All service users valued the flexibility and consistency of the support available at the Olive Tree. Many spoke about the relaxed atmosphere, and several service users said they felt reassured that therapy at the Olive Tree was not dictated by time limits but by recovery. Service users described the Olive Tree as a service that listens, understands and cares, with no time limits or pressures and one with a community spirit which works with you rather than against you. One service user said that the 'Olive Tree could be the vision of how good services could be'.

Many service users expressed anxieties about group therapy, and it was one aspect of the service that could have put them off joining. Indeed, a couple of people were so anxious about joining a group that they only agreed to have individual therapy. However, those service users who did join a group said they were adjusting to it and felt that the group had a healthy atmosphere. It had allowed them to relate to others with similar issues and to work on relationships. They found that group therapy had enabled them to feel that they were not alone with some of the difficulties and behaviours they perceived as common to a personality disorder diagnosis, and could see ways in which others coped.

Relationships with staff

There was an overall feeling that service users were happy with the support they received and would not want to change anything about their relationships with staff. Service users all said how good their relationships were with the staff and how respectful and caring the staff were.

Crisis support

Out of hours support for people attending the Olive Tree is provided by an outside crisis team working in partnership with the service. There were a lot of criticisms about the way the crisis team react and treat people who are in crisis. Service users felt they did not know enough to offer support as they often said inappropriate things. (An example was given of being told to take a bath or try lavender oil when someone rang up feeling suicidal). Some service users said they would not access the crisis team and would choose instead to use other ways of coping such as ringing the Samaritans or friends, or said they would just wait for an appointment at the Olive Tree.

Comparisons with other services

All of the service users had accessed various services in the past with little success. The attitude of staff in other mental health services was a theme running through a number of the interviews. Service users felt that, in many services previously accessed, staff did not understand personality disorder and were more used to dealing with people who have general mental health problems. As a result they had sometimes felt judged or 'fobbed off'. One service user stated that other services discriminated against them due to the label. They felt that they had been stereotyped and judged by psychiatrists and GPs.

A9 North Cumbria Itinerant Therapeutic Community

1 Description of the service

1.1 Aims of pilot service (from bid)

To provide:

- An itinerant service allowing the possibility of multi-disciplinary assessment of service users' and carers' circumstances and needs … comprising social and psychotherapeutic dimensions … to determine the most appropriate treatment pathway… leading to ... advice and support to service users, carers and professionals; outpatient psychotherapy…and/or preparation for the intensive psychotherapy day programme.

- An intensive group-based treatment … a Democratic Therapeutic community (DTC) … on two sites across the trust for (initially) one day each week. It is anticipated that this phase of treatment will last up to eighteen months and that 12 - 16 service users could be treated at each site.

- To co-ordinate services for personality disorder service users across North Cumbria … by supporting the work of other agencies including social services, probation, police, primary care, housing and the acute trust through supervision, consultancy and through further developments of the existing multi-agency, experiential personality disorder training; providing secondments for workers from a number of agencies to allow "on the job" experience and training; developing clear links with the regional forensic service and the new regional forensic Personality Disorder Service in the north east … and actively liaising with and supporting local assertive outreach, crisis intervention and primary care teams.

1.2 Staffing the service

This service is led by two psychoanalytic psychotherapists, one a consultant psychiatrist in psychotherapy acting as clinical lead: both have a 0.6 FTE secondment from the Psychotherapy Department. In addition, two half-time psychotherapists, one delivering art therapy, and two full-time outreach workers, deliver the TC, supported by a part-time secretary (0.6WTE), an Expert by Experience (0.6 FTE) with a remit to develop web services and facilitate user involvement, and a psychology assistant. The team took on a part-time project manager to facilitate business operations from mid-2005. The team has one outreach worker with a background as a senior Registered Medical Nurse, but the other outreach worker post has been vacant for some time.

A democratic therapeutic community (DTC or TC) is a model that is demanding of staff time, especially with after-groups and the need to travel (40-60 minutes) to the venue. Pressures on staff time mean that it has been a struggle to find space to bring all the staff together for team supervision and reflection away from the community: as other pilots have found, part-time work exacerbates this problem. Therapeutic community principles of containment and processing are applied to staff management. In this service, the secretary has close contact with service users (eg in handling travel expenses) and certainly benefits from supervision.

A number of competencies are identified as useful to the work. 'If you're running a TC you need some core psychotherapy sort of competencies, and you need people who understand the mental health service, and you need people who … know about psychiatric emergencies, to know what it's like when somebody becomes psychotic, maybe the best way of dealing with somebody who becomes violent. It's not that you necessarily have to put all this into action, it's that within that staff group, there are people who feel comfortable with certain things.'

1.3 Client group and referral process

Most service users using the services have moderate to severe Borderline PD, with other traits and disorders: a particular PD diagnosis is not a criterion for the service, although a score of over 50 on PDQ4 (a self-completion assessment) is usual. The category of PD is less important. A less explicit criterion is self-recognition of problems in functioning, and some desire to explore these: 'if you have somebody that is just that little bit curious, you can work on that.' Members may well have 'forensic histories', but no-one actively involved in a court process can join the TC until proceedings are completed because of uncertainty of outcome and the possibility of skewed motivation for treatment under these circumstances. Likewise, SUs must not be detained under sections of the mental health act. SUs must be as free as possible to make an informed choice about entering the service. Self-referrals are not accepted: referrals are through 'single point of access' in the CMHTs', so all the service users are on CPA although the TC does not initially hold CPA responsibilities until engagement seems relatively secure. Service leads feel that they are seeing people with moderate to severe disorders and very chaotic lives. In retrospect, this was a difficult group with which to develop a new TC: but seeing service users of this nature in one-to-one services is also difficult, and favouring service users with less severe difficulties might have been deemed unethical. Many of the initial TC group did not stay in treatment beyond six months but some remained in the service later returning to the TC or joining one of the outreach relationship groups. The TC had to rebuild its membership but continued as a working community throughout.

In the first year of operation from March 2005 staff were deciding who (from the pool of referrals to the Psychotherapy Department) to assess and offer admission to the DTC, but it was planned that members should increasingly take on this role. Discussions with members suggested they were anxious about denying treatment; but conversely also unwilling to share attention: 'when there's more members come in, we're going to have to share what we get now, we're not going to get as much'. Plans to share responsibility for assessment and invitation were in place as at March 2006: discussing new applicants will be extra material for the community to work through. Following initial assessment by staff prospective members now attend a 'selection day' at which elected SU members join staff in introducing candidates to the TC, interviewing them and voting on their membership (SUs always outnumbering staff in these groups).

There are issues around accessibility in a population dispersed over 2,000 square miles: the TC at Aspatria is geographically more central to the area than the Carlisle team base, but some members still face a 2 hour drive (from Millom, in the South). SUs are seen by outreach and for assessment at a number of sites across the Trust including, as necessary, home visits. SU members of the TC attend from all parts of the Trust catchment area. Aspatria is reasonably well-connected by bus and train. Members are generally unemployed and travel expenses are paid. The outreach service has set up 'relationship' groups in Carlisle, and West Cumbria. The service also responded to the issues of accessibility by developing the website for service users. The service feel that access is equally challenging for all service users, rather than being more difficult for one group that another.

1.4 Model of intervention, expected outputs and outcomes

The service is run from the North Cumbria Trust Psychotherapy Department outside Carlisle, with which it shares a referral process and referral meeting and clinical governance arrangements. North Cumbria has a population of 314,000 spread over 2,000 sq. miles. The pilot aimed to initiate two democratic therapeutic communities based in Aspatria (a small town in central Cumbria to service the west of the region), and in Carlisle (to service the east of the region). By March 2006 only the Aspatria community was set up, due to flooding of the proposed Carlisle premises, and the subsequent realisation that resources might be insufficient for both. The TC accepts referrals from all parts of the county, and is run from rugby club premises. Staff, together with laptop, printer, notes and art materials travel on the two days of the TC from Carlisle to Aspatria.

The DTC offers many of the features considered to be vital to treatment with this group: 'a clear structure paying attention to boundaries … a coherent model… a well-contained staff group …reflective space for members and staff'. The model is 'borrowed' from that of Henderson Hospital: hence the democratic structures, the conditions of membership, the 'top 3' posts for community members and something of the staff supervision and support mechanisms were not left to the community to decide. Although the structure of the TC was borrowed from the Henderson model, members have been involved in developing rules suited to a non-residential facility, which many prefer because it allows people to 'practise their skills' according to one member; and the major trauma associated with moving in and out are avoided.

The service liaises with CPA providers, and takes on CPA responsibilities once service users are engaged with the TC. The service is well integrated with the Psychotherapy Department: referral and clinical governance meetings and assessments are shared, so the individual is matched to an appropriate assessor (two ideally), and is considered for a range of therapies, and need not follow a common stepped pathway. Some referred service users might be best suited to be outreached for the TC, use the TC and move onto outpatient psychotherapy, whereas others might begin with individual, group or systemic psychotherapy sessions.

The TC opened in Aspatria in March 2005 with 8 members; by January 2007 this number had risen to 13. The TC runs a full day programme twice-weekly on Tuesday and Friday. The community is supported by a web-based vehicle for communication, with a members-only message board (P2P) which maintains a virtual community outside TC hours. The TC 'creates an environment where people engage in normal interactions that trigger behaviours and feelings they have difficulty with: it's got to be an emotionally safe environment, where they can reflect on and interpret those feelings, so they don't have adverse consequences.' The approach is led by psychoanalytic thinking: 'There is something about psychoanalytic training that helps you to persist with something and to keep thinking about something rather than having to do something.' The established routine of the TC day includes a staff meeting in the morning, and a parallel meeting of the Top 3, a community meeting which may be extended (at the cost of small group time) if members want; then a break after which the community splits into two small groups for more focused work. A communal lunch is followed by an activity group, usually art therapy, followed by a short after group and a final community meeting. Members have established roles: Top 3 are the user-nominated sub-group who take enhanced responsibility for promoting good governance and compliance with community structure, and mobilise the community to address difficulties requiring community intervention. Meetings have a chair and a secretary to log decisions, and the housekeeper takes responsibility for the lunch. 'Some of them are really struggling with the responsibility … even the responsibility of having tremendously easy jobs, like counting votes.' Small groups are group analytic in orientation. 'If work can be tolerated in a group situation the therapeutic opportunities multiply with considerable enlargement of the space to experience and begin to think about and understand feelings and to practice new learning, while gradually taking on more and more responsibility for self and others.'

As in all TCs, contact time with members represents only a fraction of staff input. 'Parallel processes … the staff after groups are not just about supporting staff they're about processing what's gone on in the group …part of psychotherapeutic work is not exposing a service user to all the distress … It's about the staff group being able to hold that until the service user is able to manage it themselves….And (they are places) to be fairly frank with other staff members about how you feel, and what's going on for you, and, and the impact of the work. That's what would happen in an after group.'

Attendance at TC is important. If a member fails to attend, does not respond to community enquiries, and makes no contact within 3 sessions, they are suspended from both the community and the P2P facility (see below) for 3 months. However, they remain eligible for contact by outreach during this period to prepare for re-entry to the community or to consider other options.

'Having a clear structure about paying attention to boundaries, about having a coherent model, about having a well-contained staff group, about having reflective space… Those are the things that these people have missed out on in their early years….consistency, reliability, having parents who think about you about what's going on and who plan or ….discuss or try to work out the best thing ... All things the TC can provide… And it can be atheoretical so long as you have those guiding principles. '

There are difficulties associated with the location: the need for staff and members to travel has reduced hours they can run, and created security issues. Members continue to want one-to-one attention; within groups, it is clear that some members meet and talk outside TC. However, 'There was also a wish to keep some things outside the culture of enquiry that you're trying to operate, so there were things going on outside the group that were actually against community rules and that we weren't able to capture. This is all part and parcel of the work, there's nothing surprising about this … You're not in treatment until you've broken a rule, you know. If you come along and just blindly follow the rules then actually you... it's quite possible to spend a long time in the institution and make no changes at all. And it's actually in finding yourself in a difficult position in relation to the rest of the community that some work takes place …'. There is also a need for more members to increase interactions and learning and to permit more roles to emerge, as well as to put staff into minority position: a target of up to 20 active members was suggested, at different levels of familiarity with the TC model, as it was suggested that initial confusion was contributing to a high drop-out rate.

P2P

P2P (peer to peer) is a web-based support system accessed through the service website. As well as offering local information on the TC, local services and links to national services, the website has a message board confined to DTC members, and is an innovative means for members to offer support outside community hours, under the surveillance of Top Three. It is reported that Trust Health and Safety and Clinical Governance boards were very reluctant to authorise the initiative, seeing it as signifying a loss of (surely rather limited) control over risk management with these service users. Protocols and Terms of Use for the P2P Website Support (www.itc4u.org) were sanctioned by the Trust in July 2005, and the system went live in August 2005. Guidelines for users include a ban on posting imminent threats of violence, including self-harm. P2P can be a message board on which support is posted, or can be used for live chat. Direct conversations on line are planned so they can be monitored by at least two of Top 3 (part of the risk protocol). There are strategic measures to discourage one-to-one, and encourage community, discourse: and Top 3 moderators can access and delete inappropriate message board entries, and make a verbatim log. Top 3 therefore decide what is brought back into the community. Staff do not have direct access to the message board unless requested by the community but do receive postings of 'significant events' by top 3. Use of the message board can be withdrawn from members who don't regularly attend meetings as it is an extension of, rather than substitute for, the community.

Set top boxes which allow internet access via a phone line cost about £110 and are loaned out to those without internet access (as they are cheaper than PCs). The service employs an XBX who has been very active in developing the service. Staff report that P2P has advantages over telephone contact beyond surveillance. 'On the telephone, you can just blurt and you can be in a panic and you can say I need something now. If you're actually able to compose a message and then wait for a message you know, wait a few moments for a message to come back, rather than having that immediate link, again I think it creates a thinking space for you, it helps you to sit with the feelings.'

Outreach and relationship groups:

The outreach workers (who should fill two WTE posts) operate in several ways which extend both the TC, and potentially the Psychotherapy Department. A key motivation for the project was to capture people who weren't engaging. 'We might even do a home visit now …so it's gradually evolving into quite a flexible model.' The outreach team engage with people who may or may not come into the therapeutic community. They may work to re-engage those who have dropped out of the TC, and liaise with or co-work cases with other workers. They may take forward issues arising in TC for members, and may work with families and carers, possibly with support from the systemic (family) therapist in the Department. Outreach work may develop along specific lines, but is tailored to need arising. One example is the family of a person referred who have a long history of conflict with services and may themselves have qualified for the diagnosis recently applied to their son. There is also a small self-run carers' group for this client group, which grew out of a similar one aimed at families of people with schizophrenia. 'I went along and talked to them… Carers are usually an important part of somebody's recovery really. They can hinder but can also help.'

Another role of the outreach facility is the running of groups aimed at people who are as yet unable to commit to a TC. This was adopted by the pilot from a group set up for people who could not engage with psychotherapy. Called the 'Relationship Groups', they run for 90 minutes one a week and provide a more structured approach to helping people explore group work. Staff who facilitate the group take a more directive stance than in groups at the TC with the aim of fostering engagement in the group. They are used as treatment in themselves but they are considered primarily as a means of preparing people for more intensive work such as outpatient or the TC 'The groups help them to get used to the model'. In January 2007 15 service users were using two Relationship Groups on a regular basis.

1.5 Indirect Service Provision

The two 'founding' clinical leads of the service have designed and are delivering a 15-week evening course for professionals from public services, based largely on giving participants experience of small group work and of 'applied psychoanalytic thinking' in working with people with personality disorder. The fifteen week course, a significant commitment equivalent to two modules of an MSc, has now been completed by more than 90 professionals (by June 2006) from across multiple agencies and is booked for its seventh iteration with a waiting list for further courses. The course is run approximately twice a year for 16 people, within 15 three-hour evening sessions, and combines seminars and two small reflective psychoanalytic groups. Extensions to the training are planned through 'one day refreshers' open to all previous members of the course, and three one-day per week secondment to the DTC is available to training 'graduates'. Training is evaluated (see: Rigby & Longford, 2004) and contributes to the local profile of the service. As members of the NIMHE NW PD Trainers' Network (T-Net), the service liaises with the broader PD training initiative in the region. The course pre-dated the pilot funding, but local workforce money has long expired, so the resources are found from the pilot money. Other, shorter formats are being targeted at teams working within health, social care and criminal justice: a one or three day training course, centred around interactive seminars and discussions of cases brought by participating workers, is being taken out to individual agencies. Time permitting, the two training leads would like to offer a team day at least annually to all CMHTs and specialist mental health teams. 'And we've developed a workbook which we send out to the team so they can actually work through it and read it because you haven't got the time to work through it in just a day. The workbook is quite straight forward, talking about what is personality disorder and picking up on the analytic frame, analytic model and also thinking about the major defences. Give an example of what is splitting, how can it be identified within a staff group. All these terms we know but for support workers and CMHTs, this is something new.'

The team also visits health and CJS (including A&E) agencies across the region, to raise awareness of the ITC, build relationships and thereby increase the potential number of referrals, improve care pathways and create opportunities for consultation, supervision and training. Links have also been made with the voluntary sector such as Mind and Making Space.

1.6 User Involvement

North Cumbria had very little infrastructure for service user involvement. From the development of the bid, strategic involvement of Experts by Experience (XBX) and ex-service users has been important, with contacts gleaned from national organisations, such as Borderline UK. The service employs an Expert by Experience, whose hours have been extended from an initial 6 hours per week to 0.6WTE for an 18 month period. As a member of the TC, the incumbent has a dual status which may have disadvantages as well as advantages.

The democratic TC is a model in which service users make a major contribution to therapy and recovery of the community members. Service users have developed the DTC from a baseline of no experience of such services, and their expectation of a passive relationship to therapy has been slow to change. A key element has been the assumption of responsibility for the rules and design of the service: 'Using staff as a resource, they were able to develop a very comprehensive set of community rules about, about conduct and they designed an operational policy which we're still using and we're still developing.' The TC model demands that they take on certain jobs, and chair and record meetings, and this has been a new experience for some. Service users have also participated in the Royal College of Psychiatrists' 'Community of Communities' initiative, helping to cement the adoption of the model. With the acceptance of new, service user-led recruitment to the community, members are increasingly taking on ownership of and responsibility for the service, and acquiring confidence in their abilities while doing so. In line with the Henderson Hospital TC model, the members will also become responsible for taking new members into the community. If the TC is able to recruit more members, user involvement in TC business and in the Trust generally will become less burdensome and draw on a wider pool of experience. Commitment to service user involvement (based on added value) is not well developed within the host Trust, and there remains a shortage of service users who are both experienced and well enough to be involved.

2. Achievements and capacity of the service

The first DTC opened in Aspatria in March 2005 with a programme including intensive group analytic therapy and art therapy. By March 2007, the DTC was running for 2 days, with 13 service users regularly attending and around 29 engaged with outreach services. 13 were engaged with relationship services. Including those in assessment and new referrals, there are a total of 79 people engaged with the service. The service felt that there had been some work to do to inform people locally that their work went beyond just those engaged directly with the TC. The service had experienced one sudden fallout of members early on, but continued functioning and some members have been brought back.

Because of the shortages of qualified staff in the region, the TC has inevitably drawn upon some of the resources of the host psychotherapy department but has also made significant additions to the range of services available, including outreach, as well as the TC and Relationship Group.

The peer-to-peer (P2P) web-based support system has been a truly innovative model for a dispersed community. Members of the team have written a paper about P2P which is currently being considered for publication in a peer reviewed journal (Psychiatric Bulletin). The service also feel that this internet support enables the "leaner" style of TC (2 days) per week to provide successful outcomes in the same way that a more intensive TC can. They feel that this model could be rolled out to other TCs.

The fifteen week PD course is one of the clearest and most committed programmes of training available among the pilots. The outreach service is an innovative extension to services based in psychotherapy; and its remit to engage with carers is unusual among the pilots. Well over 100 people have been through the multi-agency training as of March 2007.

3. Departures from original specification: drivers & impediments

The original bid specified that two one day TCs would be provided supported by out of hours internet support. The Aspatria TC was set up to cover the central-west. The intention had been to set up one in Carlisle, but the service was unable to due to flooding. The service felt that a better model might be to consolidate the service in Aspatria and provide a two-day per week TC and so negotiated this with the Department of Health. Service leads feel that this model provides better containment for service users, and has allowed a more useful and varied programme to be delivered. On reflection staff suggest that a one day per week programme may have been insufficient to provide a contained service to its users.

Recruitment continues to be an issue and a longstanding staff vacancy has limited the capacity of the outreach function. The plan to host more secondments has been hampered by staff shortages in local services. The North Cumbria service is possibly affected by uncertainty more than the less rural pilots. Users are unlikely to commit to the community if they think it may close. Staff have limited job opportunities in this area, and may need to respond to opportunities if they arise.

It was hoped to integrate a facility for DBT into the wider service model, and although this has not been ruled out, the dearth of DBT specialists (there are none in the Trust) has not enabled this to be delivered. Links with Community Forensic Services have been difficult to forge: there is no forensic service in the host Trust. However series of joint meetings have taken place between staff of the pilot and forensic services in North East England and the service lead sits on three forensic panels in the area: the trust forensic services development group, the East Cumbria mental health and criminal justice sub group and the Cumbria forensic criminal justice and mental health group.

4. Findings from local evaluation and audit.

As of June 2006 the ITC had received 102 referrals of which 82% had received services from the Therapeutic Community, the Relationship Group or the ITC Outreach Worker. It is reported that for service users who attended the Therapeutic Community for at least six months:

- Suicide attempts fell by 69%

- The number of self-harm incidents fell by 48% and there were highly significant reductions in impulsive behaviour and thoughts.

- Admissions to A&E fell by 26%

- Admissions to psychiatric hospital fell by 50%

- The number of days service users spent as an inpatient in a psychiatric hospital fell by 90%

- Contact with the police fell by 70%

- The total saving to the NHS through the reduced usage of other services by service users currently amounts to approximately £ 240,000 per annum and is expected to increase cumulatively, as improvements in health are maintained.

5. Areas for future development

The possibility of fully integrating the work of the pilot service with the Psychotherapy Department is being explored. One option envisaged is a tertiary service situated within mental health services offering a range of therapeutic services to service users with tier 3 and 4 problems, including those with moderate to severe personality disorders. The service would provide outreach work; formal psychotherapies including individual analytic, group analytic and systemic therapies and some less intense preparatory and supportive groups; and an intensive treatment programme based on a therapeutic community model. This could give users a wider menu of options and make the best use of available resources.

A new challenge for the service is that the trust now covers the whole of Cumbria. There is now a new agenda for developing the service. A selected development group has been established to address what resources are needed in the south. Issues there are similar, in that it is a semi-rural urban area. Barrow has significant difficulties in the same way as Carlisle and Whitehaven. The service would like to see the current service preserved and a similar service established in the south based around a new centrally places TC suitable to the area.

6. Summary of lessons learned by service providers

- Clear and regular communication between the pilot and the Trust and other organisations is necessary to ensure a consistent, safe environment for service users.

- Outreach is an important means of helping service users and carers engage with the service and expand provision to people with different problems and needs.

- Using a non-NHS site has advantages, but also raises issues for containment of staff anxiety, managing risk and logistical aspects of moving equipment off-site.

- Administrators working in a PD setting need people skills and flexibility beyond those normally required by in other settings. They should be provided with extensive support.

- Expert-by-experience roles require the individual to have made significant progress in their own therapy. They need to have high levels of self-awareness, the ability to maintain good boundaries, and access to personal supervision and peer support.

- Internet support for service users offers a valuable source of peer support at all times and from a range of locations. This is a model which could be useful for other services.

- Psychoanalytically and systemically informed training can complement the clinical work of the pilot and considerably assist communication with, within and between other staff groups.

7. A Summary of Service Users' Views

A total of ten people were interviewed in Carlisle, three men and seven women. Of these ten people, three were ex-service users and one was a carer, leaving six current service users (five women and one man). Interviewees had been in contact with the service between four months and four years; they had used the therapeutic community and a range of groups. Service staff identified people willing to take part in the research. The service user researchers then selected from these, according to research sampling criteria, and contacted participants directly.

Note: In contrast to some other services, staff at this service helped researchers get in contact with three ex-service users who were highly critical of the service. Their views were not wholly in keeping with those of current service users interviewed.

Information and Beginnings

Some people had found the written information they received about the service useful. However, some described the leaflets as confusing, and felt that the information needed to be more specific about the service and what to expect. There was a lot of uncertainty about what would be happening in the therapeutic community and in the groups. The main reason people decided to use the service was that they were told by people in positions of trust that the service would be helpful for them. Many of the service users had been in contact with mental health system for years, and viewed the service as a last chance or 'last resort'. Almost everyone interviewed said that the need to meet other people with the same diagnosis was a big factor.

The coming in process was hard for some people; one person described it as draining, another found it upsetting as it brought back memories of being ill. However, all felt that they could ask staff questions during the process. Issues arose about it being a new service; one person said that they felt like a guinea pig and that the staff were not sure what to expect. Some people present on the first day described it as chaotic.

Diagnosis

The diagnosis of borderline personality disorder (BPD) or just PD was given to most of the service users just before they joined the service; only a few people had had the diagnosis for more than two years. Views about the diagnosis were mixed; some were not happy with the diagnosis, whilst some found it useful to (finally) have a diagnosis and have something to work with. For some people, the diagnosis had had a major effect on the support available to them; they said that all support outside the ITC had been withdrawn.

Rules and Conditions

One of the major themes to arise at this service concerned the rules regarding peer relationships at the ITC. The service forbids all contact between service users outside of the group therapy and discourages any one-to-one contact. For example, service users said that they were not allowed to go outside to smoke in twos, and were not allowed to travel to and from the service together, even on public transport. These rules and conditions were a major source of dissatisfaction for the majority of interviewees, and were said to be a major factor in people leaving the service. However, there were a few people who supported the rules, saying that they were needed to maintain boundaries and ensure that everything was discussed in the group work.

Group Therapy

The predominant vehicle for support at this service is group therapy. Many service users were very critical of this, saying that they felt they did not receive enough support. Only a few people were positive about it or about aspects of it. One person said, "You have 15 minutes to open yourself up" and did not feel there was time to put themselves back together. There also seemed to be some confusion about what they were supposed to be doing in the group work. Several people said it was common to sit in embarrassed silence; many felt that the staff needed to be more directive or that it needed to be more structured. The majority of the service users expressed the wish for one-to-one therapy as well as, or instead of, group therapy. Some people had left or were considering leaving as they found the group work "a waste of time".

The service also offers a peer-to-peer support board on the Internet, where people could log onto a secure webpage and leave messages for the other service users to look at and respond to. Few people had used this at the time of the interviews; indeed, one person said that they had left a message and no one had replied to it. It may be that this has developed further in the time since service users were interviewed.

Crisis support

Many people said that the service had no 24-hour crisis support line. They said that if anyone has a crisis whilst attending the service, they could call a special meeting where they can discuss the crisis in a group setting. Some people were happy with this, and would contact their own GP or CPN if a crisis happened outside service hours. General comments were that crises seldom happen solely between the hours of 9am and 5pm.

Relationships with Staff

Some people felt that there was a lot of mutual respect between staff and clients, and said that staff were very genuine and they could talk to them when needed. All had positive comments about the person who started the service. However, some said they felt unable to talk to staff, which then stopped the group work from happening. People commented on the lack of flexibility in contact with staff, or said that the service lacked a human touch (for example, it was said that they were not allowed to say goodbye at the end of a session). Many people particularly valued the member of staff who was an ex-service user.

Outcomes

Everyone interviewed had experienced some positive outcomes as a result of contact with the service, even those who were most critical. People said they had experienced a growth in confidence, the ability to mix with people, had learnt coping strategies, and were able to recognise factors that could trigger difficult feelings or behaviour. For some, just being able to attend the ITC was a positive outcome. The people who seemed to have got the most out of the service were those who found the group work valuable.

Ex- service users

Three of the interviewees had left the service, in addition to which one person was thinking of leaving. These interviewees expressed considerable negativity about the service, were critical of the rules regarding contact and did not feel that the service had very much to offer them. Some said they left the service because they wanted one-to-one therapy, and did not feel that the group work was helpful. In addition, a couple of people said they had found it difficult to access the support of mental health services since leaving.

Suggestions for Improvement

A major issue for some people was the location of the service; it covers a large rural catchment area, and some people would have to make a 70 mile round trip to attend. Most felt that the rules about contact should be more relaxed; others mentioned wanting more out-of-hours support, more structure to group sessions, and a desire for individual therapy.

A10 Leeds Personality Disorders Network

1. Description of Service

1.1 Original aims of the service (from SLA and bid)

The Network aimed to improve the management of people with PD who were experiencing distress, and had difficulty accessing appropriate care by:

- Taking on up to 60 service users for assessment, treatment and care coordination (this figure was subsequently revised to 45 following further discussions with the Department of Health)

- Developing and sustaining a service user network so that current and ex-SUs have a meaningful role in service development and evaluation;

- Establishing out of hours and crisis arrangements;

- Enhancing capabilities of staff in mental health and partner agencies (via consultation, support, supervision and training);

- Reducing stigma and increasing choice;

- Ensuring offenders with PD accessed appropriate care through making links with forensic services;

- Establishing and sustaining education and training to statutory and partner agencies to assess and manage service users with PD.

The aims of the Network were subsequently refined, and are (1) To demonstrate what works with service users (using care coordinated service users as primary examples); (2) To increase the capacity of other providers to work effectively with them. (3) To work with community forensic team to work with people with pd and forensic history). The Network has limited capacity to 45 care coordinated service users initially prioritising complex cases recruited by asking all CMHTs to nominate service users who had PD and who they were not making progress with.

1.2 Staffing the service

The Network had 27 staff members (22 WTE) by February 2006: care coordinators of nursing/social work background (4), 1 clinical team manager, psychologist (1), assistant psychologist (1wte) psychotherapists (3 x 0.5 FTE), healthcare support workers (4), 2 voluntary sector workers employed by Touchstone (a local Voluntary Sector organisation), a clinical specialist OT (as of Sept 2006), a service manager, probation officers (2 x 0.5 – 1wte as at September 06), accommodation support workers (2 wte), an advocate (0.5wte Leeds MH advocacy group), a user/self-help worker and admin staff as well as nursing, OT and clinical psychology trainees (usually at least 1 trainee at one time).

All staff share core business of working with network clinical caseload as well as having responsibility to work outside of the network within their own agencies – sharing skills and knowledge that they have developed through working with service users in the network (mapping to the revised aims 1 and 2 of working clinically and enhancing capacity). They are managed within host organisation but brought together to work within the network.

Staff competencies required are those linked to each worker's discipline or agency; understanding and application of Livesley's framework (see below) of care coordination. They are also required to understand and apply risk assessment and risk management and show commitment to clinical supervision and to the development of reflective practice. The service manager said that the decision not to employ a psychiatrist was made because it was unclear whether psychiatric input would be a cost-effective use of resources. The Network set out to appoint therapists who could have had a background in psychology or psychotherapy, but the response to advertising these posts meant that no psychologists were initially appointed. A senior psychologist was subsequently appointed to develop and deliver psychological therapies. It was felt that discipline-specific skills were less important at recruitment than the ability to engage with service users.

Most of the staff team came together in October 2004, and spent around 6 weeks on induction, determining values, principles, etc. Staff recalled that the induction was non-hierarchical and democratic: everyone could have a view, policies were formulated, negotiated and owned by all parties. Induction included training (for unqualified staff too) in International Personality Disorder Examination, genograms, Avon assessment, and Young's schema. This period was said by all staff to be their major source of training in Personality Disorder, assessment and management: it also functioned as teambuilding, and enabled the team to contribute to matters of policy and practice. However, those who have since joined the team may feel less well integrated. Although the Network days are opportunities for inviting external experts and trainers, some staff felt that ongoing training was not given sufficient emphasis. Supervision is by profession: seconded professionals on 0.5 secondment continue to receive this from their host agencies.

The last Friday of every month is Network Development Day, when all staff attend the central base for shared training and discussion of policy. There is a business meeting and then development time which can be used in a variety of ways. Only the Project manager, psychologist, care coordinators, healthcare support workers, assistant psychologist, OT, trainees and admin staff are based at the Network premises. Other staff are based in their own agencies and service users are seen in service or home settings. Notes are kept on the Network premises, so all staff have to come in at some point to complete them. There was originally a weekly assessment meeting, lasting 1.5 hours per week. This was subsequently increased to 2.5 hours per week in order to allow a detailed review of the assessment and treatment. Two service users are discussed each week. Staff feel that an important part of supervision and peer support relates to the impact of the work in such a service. 'What's become apparent is the emotional weight of the work: there's no good stories in assessment. There's a difference in PD being the whole – not just part – of your caseload.'

1.3 Client group and referral process

The Network set out to care coordinate complex cases, and to add value to the work undertaken locally by other services seeing service users with PD by offering support, education, etc. There were no rigid criteria for 'complex cases', but being on enhanced CPA, having a 'chaotic' presentation, poor engagement with services, being high risk, and high levels of emotional distress – were all considered important. There has been a process of teasing out how best to measure complexity.

Originally service users had to be referred by CMHTs or a community forensic team. Since then this has been expanded to include referrals from the local crisis resolution and home treatment teams. Initially the 12 CMHTs and the local community forensic team at Leeds Mental Health Trust were invited to refer the two PD service users they had most difficulty in moving forward. Residence, or a GP, within the Leeds postcode area is also required. The network holds care coordination, but links remain with the referring team, for instance, they may continue to see a psychiatrist for review of medication. It is a network principle to get the referring team to agree the referral, not just the worker. In a climate of scarcity, the Network seeks consensus from the referring team that all available options are exhausted. The Network only takes on service users for care coordination if staff feel they can deliver something that the CMHT cannot deliver with Network supervision: 'The clients who are beyond the reach of the CMHT, or the clients who have exhausted the CMHT resources.' The Network has the resources for assertive outreach where needed.

High risk, frequent crises and high demands are the main reasons for referring. Approximately 70% of referrals are female, 30% male. The service feel that there is a perception in local services that males externalise aggression while females are more likely to self-harm. This means that men are more likely to be seen in the Criminal Justice System, while women are more likely to be offered community mental health services. However the experience of those working in the Network is differences between genders in behavioural problems are not as great. Very few service users are actively involved with criminal justice services. While one of the seconded probation officers identified at least 25 potential service users on probation, these service users were ineligible for the service as they were not registered with a CMHT or the local forensic service. Around half of referrals for care coordination received in the first 18 months were offered assessment suggesting at least 50% did not meet service criteria for direct client work but may have been offered consultation instead.

93% of referrals in the first 18 months were White British. Two members of staff specialise in considering the service from the perspective of BME service users and carers. The service is trying to think about issues of access for this client group and how to improve this. Improvement for this also needs to apply at the point of entry to CMHTs: there is concern that people of minority ethnic backgrounds – particularly those who do not speak English fluently – may be excluded at this stage. The Network has therefore tended to reproduce the exclusions applied to this group by mental health services generally. In addition forensic/probation referrals cannot be accepted for care coordination unless a CMHT or the community forensic team can be persuaded to taken them on. In some cases consultation may be offered as an alternative. The service sees developing the relationship with the community forensic team as a key piece of work.

1.4 Model of intervention, expected outputs and outcomes

Leeds Personality Disorder Clinical Network (sometimes referred to as Leeds Managed Clinical Network) has an HQ in business premises away from Trust services, but service users are not seen there. The Network is effectively managed by a Board led by the local PCT and MH Trusts: the bid involved the Mentally Disordered Offender Partnership Group, Leeds MH Trust, Social Services, Police, Probation, Housing, Voluntary Sector support service. The population of Leeds is about 750,000, spanning five PCT areas, with 12 CMHTs and one Community Forensic Team.

The service model has similarities with assertive outreach approaches in terms of the amount of effort it makes towards engaging service users. This will involve meeting people in their homes, or mutually agreed places in communities, persisting in contacting people despite cancellations and non attendance. The challenge for care coordinators has been to decide the cut off point of when a service user is unwilling to engage in the assessment process. The assessment process can take up to 12 weeks. The service sees this as an important part of the intervention process. Part of the lengthy assessment also focuses on the relationship between the service user and the existing team in that they may look for repeated interpersonal patterns. The assessment may highlight 'unhealthy dependency' in either direction between current keyworker and service user. A comprehensive assessment report is shared with the service user, and the referrer. In many cases, the outcome of the assessment is to provide a number of recommendations, either for care coordination within network, recommendations around how to help services work with service users, or signposting to other services. The Network has the capacity to care coordinate 45 service users, but had not exceeded around 30 in its first 18 months. Every service user accepted will get a care coordinator plus a health support worker. A CPA care plan, with agreed goals, and a crisis plan, is formulated. Goals may range from improving social functioning e.g. being able to travel on a bus, to more psychological changes such as the reduction of self-harm. Emphasis is on the service user taking responsibility: the team is there to support.

Interventions are underpinned by 5 therapeutic principles as described in W John Livesley's 'Practical Management of Personality Disorder' (2003). The network attempts to organise interventions according to the framework proposed in the book. This outlines phases of: safety and managing crises; containment; control and regulation (improved self-management of emotions and impulses); exploration and change (of underlying cognitive and affective structures); integration and synthesis. The service aims for outcomes for service users of improving people's quality of life, reducing symptoms and levels of distress and reducing inappropriate use of services such as A&E, admissions to hospital etc. Social and practical support from the team is available to those who are care coordinated, as is therapy. 'Cases here get a care plan, structured input, a lot of contacts, engagement in leisure activities, problem-solving …a positive relationship, pro-social modelling.'

The network offers a number of therapeutic interventions: accommodation, social, occupational and psychological support and skills; medication management, as well as formal psychological therapies. The case management model provides structure, reduces chaos, and provides containment and support for service users. Service users will access different packages within the framework. Some may not be able to tolerate formal therapy: so the outcomes may be more around external containment rather that internal change. Psychodynamic, CBT, group analytic, intercultural therapy and recently DBT-based skills training are all available within the network, A psychologist was recruited some eight months (June 2005) after the team came together to consider, implement and evaluate psychological treatments: staff report that it is unfortunate that the psychologist was not in post when the principles of the new service were explored and established. This has meant that while a number of psychological therapies are now available, they are not underpinned by a unifying model.

The very thorough holistic standard assessment is designed for the case management model rather than intended to include a specific assessment and formulation for psychological therapy. If it is thought after the initial assessment that the service user would benefit from formal therapy, they will then go on to receive an assessment and formulation within the psychological therapy process. For other service users the most appropriate intervention may be something different, for example accommodation support. Whatever the outcome, the decision is made collaboratively between the network and the service user. Psychological therapies, if identified, would need to be delivered, or at least reinforced, by those in primary contact with service users: hence any psychological therapies must be owned and supported by a skilled-up team. Therapists see service users who are care coordinated in the network. If the network is care coordinating 30 of the most complex service users, they may only be able to engage for example a third in therapy. The therapist role is not only in the delivery of direct formal therapy, but also in helping the rest of the network to retain and develop further psychological thinking. Other interventions, with support from the therapist, may also be framed in psychological terms.

According to the clinical lead, therapy should aim to: reduce distress; increase ability to manage distress; increase functioning in relationships and within the community; increase self-esteem and deliver any aims identified by the service user. Service user ownership of goals is important. The clinical lead was at the time of interviews keen to introduce schema-focused therapy as a unifying philosophy to underpin clinical work for all care coordinators. At the time staff tended to draw on their individual clinical backgrounds and without a unifying principle to work to they did not have a shared understanding and language to understand the service user's distress. Since then, she has realised that a more flexible approach may be more realistic. Different care coordinators can work without a unifying model, but there needs to be a level of governance of the way in which people work. For the therapists there is also a need to be able to draw on a number of different psychological principles at different times according to a service user's needs. Service users are increasingly being offered choice in the therapy that they receive, though this is naturally limited by what the staff have received training in.

Consistency, boundary maintenance and motivational work are all valued by the staff team as a whole. Many service users referred in may not at that point be motivated to change, which can be challenging. Limited motivation however is seen by the network to be a key part of what people with PD present with. It is therefore seen as a central part of the job of the network to work with the service user on that motivation.

Out of hours and crisis resolution services are not provided by the Network as this does not fit with the philosophy of the service. There are, however, arrangements for out of hours and crisis in the form of shared care protocols and joint working agreements with the existing Trust Crisis Resolution and Home Treatment team and Dial House (survivor-led crisis and telephone service). These arrangements can also be with a service user generated contact such as a carer. There is some evidence that crisis referrals to statutory crisis services have fallen since the Network developed. Risk assessment and management is coordinated using a comprehensive tool and all service users who are taken on for care coordination have to have this completed within 12 weeks.

The team and its steering group have commissioned a two-year Action Research evaluation (at a cost of £50,000) from University of Chester. This may deliver an audit of service activity, and a discursive group reflection rather than evaluation. The intention is to use these outputs as a means of benchmarking, and a guide for the development of similar services: but it is not yet clear (at the time of this report) how the conclusions will be backed up by evidence of outcomes for service users.

1.5 Indirect service provision

The Network has provided regular or sessional training input to student nurses, clinical psychologists in training, ASWs, probation trainees, the voluntary sector, accommodation providers, primary care staff, and OTs. They provide specific placements to student nurses, clinical psychologist trainees. In addition to the training, they provide consultation, advice and support to a range of agencies including probation, voluntary sector, prison, and NHS services groups. The Network has recently developed a protocol for a model of consultation, whereby 4 sessions of consultation are provided over an agreed time period. The Network coordinates voluntary sector forums and the Network has quarterly input to pre-registration training courses. They have also played an important role in the Learning Network events for the PD pilots.

1.6 User involvement

There are 2 service user members on the network management board, who have been in post since the beginning of service. Opportunities for peer support are limited as users do not attend a central base. There is no chance therefore to exchange views; although users do meet each other in CMHTs. Staff do not think a carer service could be established, as service users would need to agree participation. User involvement has, in this Network model, been sub-contracted to a (Mind) Voluntary Sector worker. The purpose of this has been to develop the service user involvement agenda from the service user perspective rather than the service perspective.

2. Achievements and capacity of the service

The Network has comprehensively assessed around half of the 90 referrals received in its first 18 months, and (at June 2006) had 30 in case management. It is reported that there has been widespread indirect intervention in the management of many others through consultation services.

One of the strengths of the Network model is the number of links into different services the variously specialised and seconded staff have. Seconded workers take training back into their initiating organisations and other allied services as an explicit part of their role. As there was initially an emphasis on developing clinical work and building up the Network, this training component has become more strongly established in the last year. Teaching packages have now been delivered for every agency in the network. The secondment model also provides for multi-disciplinary supervision. Staff put particular emphasis on making links between their case managed service users and voluntary and statutory services.

3. Departures from original specification: drivers & impediments

Although the work that led to the development of the Network was commissioned by the Mentally Disordered Offenders (MDO) group in Leeds, the model that has emerged is not a forensic model. The Network feel that this link was initially important to their strategic direction, but the MDO group is not a partner in the Network now. They are working regionally using a forensic catchment group but to develop non-forensic initiatives. They are the only pilot to work with a forensic population as they accept referrals from the community forensic team. The proportion of forensic referrals for care coordination is, however, perhaps not as high as originally anticipated. In addition to this, however, they provide specific consultation for forensic service users and a two day training course for a low secure women's service. They also provide consultation for the prison inreach team.

Care coordinators and support workers have caseloads of around 10 assessments over a year period, with an additional caseload of 5 for care coordination. The Leeds Network claims, in its relationships with other providers, a lot of expertise. The Network's case management model has particular strengths in engagement and containment of service users. The staff see care coordination at the heart of enabling service users to access therapeutic and other interventions within the Network and much of the emphasis is on providing this. As the service has apparently reached capacity, however, there may now be a need to focus on moving service users through the Network.

The main departure in the Network is that they now only offer 20 places for care coordination. In lieu of the other care coordinated places they have now commenced a day treatment programme with 30 places over a year. The day treatment model complements the Network in that it can address occupational and social inclusion issues and is broadening the service user base. They also offer the assessment process over 12 weeks for 40 people over a year. The consultation and training aspects of the service have also grown significantly from the original specification. In addition the referral base has expanded from CMHTs and the community forensic team to include the Crisis Resolution and Home Treatment Team. This has introduced a new issue for the service of potentially bringing in people who are not in existing mental health services. The Network has developed the role of gatekeeping, which was not outlined in the original specification. They are asked to screen any service users who are referred for out of area placements. They take on a central role in developing the pathway protocol for the region.

The Network is also starting to look at work with no fixed abode populations in more detail. There is also a piece of work around MAPPAs with the forensic service. In addition the evaluation from the University of Chester will wind up by October 2007 and will pull together the various strands of the service.

4. Areas for future development

The Network has spent much of its time thinking about what is offered in care coordination. The focus has been on identifying, agreeing and negotiating treatment goals and establishing how they know when they have achieved these. Discussion at the moment is moving on to think further about discharge and thinking about delivering care coordination within 100 weeks. The Network is keen to think about when is the most appropriate point to think about discharging service users and what the most appropriate pathway beyond the Network is.

5. Summary of lessons learned by service providers

- Because there are no established models for providing dedicated community-based services for people with PD, services need to continually review what they do and consider ways of improving the service they provide: there are 'no plateaux on the learning curve'.

- Collaborative learning is essential – this process of review needs to include the perspectives of a range of service providers and users.

- Helping clients with practical/ social problems can help build trust in the early stages of engagement.

- Risk management needs to be shared with the whole team and not held by individual members of staff.

- It is essential for therapists to maintain reasonable levels of hope.

- The personal characteristics of staff are important: they need to be brave, to be able to tolerate anxiety and cope with the strong emotions of people with PD.

A11 Plymouth Icebreak Service for young people

1. Description of Service

1.1 Original aims of pilot service (from SLA and bid)

- To target people aged 16-25 who are at risk of social exclusion but not necessarily diagnosed with PD.

- To improve social cohesion and social capital; provide new services driven by service user need; reduce self-harm, suicide, prison admissions & stigma; support carers & dependents; overall 'to promote a more positive experience of life' (leaflet).

- To provide assessment, care planning, case management; access to telephone service 24 hours a day 7 days a week and outreach work

- To case manage around 35 service users and offer some services (e.g. signposting, support) to up to 55 others.

1.2 Staffing the service

Icebreak is a care coordination service for young people (16-25) who may go on to receive a diagnosis of personality disorder. The service provided aims to assess need and arrange for its delivery, with an eventual aim to avoid the social exclusion associated with personality disorder.

It is situated within the Zone (previously known as the Youth Enquiry Service) which is a large-fronted, highly visible, walk-in service near the City's main shopping area.

The bid specified a staff team of one team leader which was established as a post in June 2006; 7 x care coordinators (they have 6 plus time bought in from the personal development programme workers internally for group activities); 0.2 of a GP with Special Interest in mental health (GPwSI) and input from a consultant psychiatrist from Plymouth psychotherapy services. Staff were to be in post by August 2004, with the service to be operational by October 2004. In August 2005, the service had only 6 care coordinators (CCs). Three of the original CCs came from youth services and all came from a range of backgrounds including a CPN, a counsellor, an ex-policeman and foster carer who has been with the service since its establishment. As at April 2007 3 of the CCs are mental health nurses. Between them, the range of skills – or perhaps interests – brought by CCs has included CBT, DBT, drama workshops, and creative arts. Two of the initial six care coordinators were within the age group targeted by the service.

The initial service manager (of CPN background) was responsible for all health-related teams on site, i.e. Insight, Icebreak, Counselling and Supporting People and was somewhat overloaded. At the outset, the skills base of the team featured some recognised advantages and disadvantages of working with non-clinical staff. It has since been recognised that a professional qualification is a requirement for this work, such as a qualification in nursing, social work or youth work. Though lacking predetermined prejudices, the first staff team needed reassurance and support around issues such as self-harming and suicidal threats among service users. Five of the six original care coordinators had no experience of risk management before joining the service. The key recruitment criteria were ability to empathise with and gain the confidence of service users. The team have since been through a learning process with recruitment and now realise that as well as these criteria coordinators should also have significant experience of working with vulnerable young people at risk. The service now look for people with those skills and expertise already in place when recruiting, rather than having to train people up in post.

Although team management has changed during the life of the pilot (as this is one of the few pilot services which has had a change in leadership), there have always been team business meetings (at which referrals are allocated for assessment, always to two team members), and group clinical supervision chaired by a clinical psychologist or (more recently) a psychotherapist. All of the young people in the service are discussed at supervisions as part of effective case management with regard to risk issues and the response or intervention that is most appropriate. All staff have monthly line management supervision. Team away days take place every four months. The team can take advantage of Trust training programmes, and staff have undertaken training in CBT (a 2-day course); solution-focussed therapy; family therapy; and unresolved grief. 'The university do offer a module on personality disorder and I wonder whether that shouldn't have been part of the pilot, with everyone doing it.' One of the service's aims for the near future is that all new and existing staff attend this module as part of their Continuing Professional Development. This was considered to be a key part of the necessary learning and development processes for care coordinators.

Some staff felt they did not want initiation into the medical model of PD, or into NHS governance. The jobs were advertised as key working in a social exclusion project, but became care coordinating for service users with emerging PD. 'There's stuff about daily records and contact sheets and risk paperwork … I sometimes think quite a lot of its irrelevant to our kind of work… I like to do the more solution focused therapy. The paperwork is problem focused and it uses that language (of) mental health problems. That's difficult for me because I can't work in a way that I want to.' As the service has developed, the service has worked with young people who pose a higher level of risk in a variety of ways. The service does provide an alternative to the adult mental health services approach, however, the CPA paperwork does not always support this as it is problem focused. Care co-ordinators do, however, see it as a helpful tool in some respects.

The nesting of the service within a street level youth agency is of benefit because it increases accessibility to the service and the opportunity to link with others in-house. Zone Managers have a duty system and if the Icebreak Manager was unavailable at times, this meant that the Zone Manager would provide cover. There were initially feelings, however, that some Zone managers were not as experienced in relation to specific PD issues as the Icebreak team members. This meant that there was sometimes a gap for the service user. Over time, the Icebreak team have informed the Zone Managers knowledge and have agreed a supportive way forward which does not leave either the young person or the agency at risk. The team has grown in confidence and capacity to respond appropriately to those service users who are anxiety provoking for staff.

There were some initial problems with staff feeling that caseloads (of 15) were too high for assertive outreach work with chaotic young people. This was especially an issue as available support from Community Support Workers was in short supply, and they were also running groups. At the time of interviews the team had no clinical lead, and only a weekly session with a psychologist or psychotherapist. They did follow Trust risk management requirements, but these were said to be more concerned with reporting than with taking evasive or remedial action. The service has since developed its own model which is distinct from assertive outreach work. The team have since gained a team leader which has proven a valuable role in terms of giving the team a focus and a place to discuss issues of concern about risk. The team now aim to work with 10 –15 young people per care coordinator for full time work. They have developed and are now working with a team approach, meaning that every young person has contact with at least two care coordinators This is done for a number of reasons: to reduce the potential risk of young people developing a dependency on one worker; to support staff by sharing the workload and the risk and to give opportunity for staff to reflect with each other about the encounter.

1.3 Client group and referral process

Service criteria are as follows:

- The potential service user must be registered with a GP or eligible to register with a GP within Plymouth, Ivybridge, Tavistock or South Hams.

- They must have no current input from the adult Mental Health Services (as the service is aimed at engaging people before diagnosis and/or MH service input; and will not work with *another* care coordinator). An exception is made if the Home Treatment Team or Psychiatry Liaison say they have only *assessed* the person.

- An exception is also made for service users of Young Offenders Team and CAMHS (as it was part of this bid to take over their service users.) Icebreak may also work with forensic services if a young person is at very high risk.

- Referrals must also have significant problems, and ideally some, however slight, motivation to be different.

- The young person must be informed of and agree with referral.

Around 20% of Icebreak service users have had contact with criminal justice services. 50% are male, higher than in other pilot services. Only one BME person had used Icebreak, but this was thought to reflect the ethnic mix of people in the Plymouth/Devon area. The Zone historically provided a specific group for refugees and asylum seekers, but unfortunately funding for this is no longer available. Most Icebreak service users do not live with their families. Many have unstable or temporary accommodation and initial work may involve helping the service user access emergency housing (B&B). Working outside formal diagnostic classification systems, the service has had inappropriate referrals.

> They weren't chaotic enough. The aspects of their personalities that caused concern and prompted the referrals weren't necessarily causing them massive problems in their lives. Just a bit odd, eccentric. We had a few that were more LD [Learning Disabilities] than PD. We're not about getting people to conform. They need to see it as a problem, or they won't engage.

The service will always engage in a dialogue with the referring agency even if the referral is not appropriate. In these cases, the service will assist in signposting to a more appropriate service for the young person. If there is not a suitable service locally The Zone is able to feed this information into strategic meetings. Young people can also still get a service from The Zone through other group work and therefore feel less disengaged.

The team initially found challenges in assessing this group of young people in terms of distinguishing between PTSD and PD and dysfunctional behaviour as compared to behaviour *normally* attributed to adolescents. Since then, with experience they have developed assessment skills and have a much clearer idea about the sort of issues to look for. Service users referred may exhibit a number of complex problems without necessarily fitting criteria for particular services: for example, they may have learning difficulties, be care-leavers approaching 18; pregnant (but Social Services is acting for the child); using drugs (often amphetamines rather than Class A drugs); dependant on alcohol; have symptoms of ADHD or parents may be heavy users of MH services. Icebreak often picks up those who fall through gaps of eligibility for other services, and so work with young people who otherwise would not receive a service despite experiencing a high level of distress. Unlike psychosis, there is no clear picture of 'prodromal' symptoms. Assessment of up to 12 weeks entails assertive outreach, engagement and fostering some motivation to change. Assessment in pairs is one way in which service users get to meet more than one team member (service users being held by the team, as in an assertive outreach model). Participation in groups is another.

1.4 Model of intervention, expected outputs and outcomes.

At the time of the research from which this is drawn, the Service was managed in conjunction with the neighbouring Insight service, for young people with psychosis. As Icebreak is an integral part of the Zone, it subscribes to the same principles of respect, development and empowerment of young people; and also builds on the experience of the Insight team (another on-site service for young people who experience psychosis: but Insight has a psychiatrist attached who prescribes medication). A Youth service approach and street level access has enabled engagement with this group (As shown in the Sainsbury's Insight Evaluation 2002) However, within Insight, more referrals are made via Gateway, which is the Trust portal to MH services, as well as from Primary Care, whereas Icebreak sees roughly a 50:50 split between internal referrals from The Zone and from traditional mental health routes.

The Icebreak service is developing its own model of intervention which reflects the development of the work they have done with young people with emerging PD.

Flexible assertive outreach techniques are used. 'Pretty much every client I phone or text beforehand to remind them that they've got an appointment with me, even if we made it the day before. Unless I know they're very on time, but if I wasn't to do that a lot of them wouldn't remember or would get caught up doing something else.'

The innovative nature of this project means that it is not evidence based. Instead work with the service users is based on generic principles for working with young people and much of what is done with service users is described as 'instinctive'. Some staff prefer this way of working (see comments above), but others find it too vague: 'It's been quite unclear some of the time what we are supposed to be doing.' The service tries to find a balance between delivering a medical model approach, a developmental youth approach and a social care approach. A key part of the intervention is to build a positive staff service user relationship whilst maintaining clear boundaries. Care coordinators see themselves as both confidantes and positive role models. 'I know I'm good at finding positive things in people and helping them recognise it. It can be the smallest thing… Low self-esteem and worthlessness, but their outward presentation can cover that up. A lot of it boils down to fear of rejection – that they won't be liked or that people are going to hurt them. My theory is I hold myself in high esteem because I've got a lot of positive relationships: our relationships with clients are like a mirror.' The team have increasingly developed a mix of skills that include therapeutic interventions, and youth work approaches, which highlight the distinction between the role of care coordinator, and that of support worker.

Care plans have to be negotiated with service users: they must agree that what is proposed is useful to them. 'For us to be there, the care plan's got to be agreed with them.' 'They're in control of it as much as possible without it being ridiculous demands'. Staff try to empower service users to sort their lives out; they also encourage them to form relationships with other services, but not mental health services.

> Co-ordinating their care doesn't mean you have to do everything for them, but you're helping them to delegate to the right people. You're almost there for advice and information: it doesn't mean you have to do everything for them. It's also about not making them too reliant on you because you never know when you're going to be away or ill or anything like that. If they haven't done these things before … it can be very stressful for them.

Like most assertive outreach teams, the service is able to give quantitatively more support than other services, and in community settings. Supporting People were providing accommodation support to the team's service users, which was thought to reduce the workload of care coordinators, but the funding was cut from October 2005. An accommodation service within the Zone can now provide limited support around accommodation for those who fit the Supporting People criteria. At the time of interviews the care coordinators themselves did not have a common perspective on the aims and outcomes of their work, but a number or summary points were made: 'I think it's about giving hope;' ; 'Building up a relationship is important, and actually being there for them and looking at them and supporting them and listening to them…' . 'My strength is about looking for positives in the past and working on them and building those as positives for the future and it's about personal development, personal growth.' Since that time, the team have developed a unified perspective on the outcomes of the work as stated in the Icebreak model. These include self-management, establishing stable social networks, becoming problem solvers, acceptance of self, narrative coherence and celebration of achievement.

Workers say they have adopted a matter-of-fact approach to self-harm and that this helps build their confidence in reducing risk. 'It's their coping strategy, a mechanism they've adopted. People assume it's close to killing yourself, but it's not, it releases the pressure building up… personally I tend to ask people about their self harm, how they do it, where they do it, how deep or superficial … So you have a conversation with them about it. And also the most important thing is to find out what things they know might make them think about doing it or want to do it.'

The Zone has a counselling service which provides a limited number of sessions to team service users and service users also have access to a psychotherapist in the Icebreak service. Because service users are younger than the clients of other PD services, they may be more embroiled in the difficulties which are contributing to the development of problems. There is general consensus that a service user who can talk about these events is less vulnerable to their impact. However, beginning to engage with such issues is likely to be understood as a trigger for a counselling referral. 'A lot of it is about young people getting to a stage where they feel secure enough to explore some of the things that might have gone on and feel that they've got a safety net there.' Not all service users need to express these events and feelings, but the team does have a number of strategies for offering that exploration. 'If they're still holding on to the past and that's shaping their personality as they are now, then it is something you need to address.'

Different strategies may be used for encouraging emotional expression in service users, drawing on the backgrounds of the workers. There is no expectation of 'changing' personality, but there is emphasis on reducing dysfunctional coping strategies, increasing stability and quality of life and integrating the person into facilities, services and relationships. The model also emphasises the therapeutic alliance, so careful attention is given to selecting the most appropriate care coordinator for the service user. The team adopts the Assertive Outreach model, in which the service user is held by the team and so there is always someone there for them.

An important part of the role of care coordinator is to refer service users to other services. For example, the team has a good relationship with MIND, who are partners and provide DSH training. Benefits advice and debt counselling can be accessed via MIND for young people. The service also has a good relationship with drug and alcohol services and so will often refer young people here. Care coordinators will also try to find appropriate activities for the young people to get involved. An example of this is a Ground Work UK project called Horticultural Healing which works with young people and adults with mental health problems. This project aims to involve service users in managing the grounds of a residential area, providing supervision. This can be a positive socialising experience for young people, and be a step towards inclusion in employment.

The service has a 'stand-alone' service user-focused evaluation (Jan. 2005 to end Oct. 2006), led by researchers from Plymouth University, which is interviewing service users and producing quantitative measures and qualitative commentary. However, some of the data collected for audit purposes is difficult to interpret.

1.5 Indirect service provision

The team has a limited capacity for consultation and training of staff from other services, although staff do liaise with other services on behalf of individual service users, and do attend professionals' meetings as required (e.g. case conferences for infants born to service users). They also circulate CPA-type care plans to other professionals engaged with the service user (who is unlikely, by definition, to be on CPA). Since the time of interviews, the service has begun to deliver training for the youth support workers in the Zone about the work they do. This is an important part of the team's work given that 50% of Icebreak's referrals come internally from The Zone. The Youth Support Workers are the first workers in The Zone to have contact with young people and therefore, have a need to understand how Icebreak could help young people and ensure that they are appropriately referring young people. They also hold visitors' days each quarter for the professionals in the region (such as trainee nurses, teachers, health professionals, criminal justice youth workers, support workers) to inform people about the service and how to get involved.

1.6 User Involvement

Icebreak feel that traditional models of service user involvement, as in place in adult services, are not necessarily as helpful or appropriate for young people. Instead they have looked for creative ways in which to get feedback from the service users on improving the service. In the summer of 2006, therefore, the team produced a DVD film in which service users described the services they had received from Icebreak and talked about any recommendations for additional services they thought would be useful. As well as being a project which the service users involved in its own right, it became a useful promotional tool. The service has aimed to implement some of the changes suggested by the service users. One of these was a drop in service for Icebreak service users. The service feel that this was a more age appropriate way to get feedback from service users, and that service users got something very positive out of it.

The role of peer support continues to be reviewed. Staff worry that service users may get into unhelpful ways of relating to each other, for example over dependence, but have run an away day for a core group that know each other: the day went well and other days out are planned. The staff are gaining confidence through the self-harm and emotional literacy groups, where interaction has been supportive and helpful. A mentoring scheme could be initiated once the service had some alumni. The service offered a carer/family group for a limited time but it became apparent that there was no up-take for support offered in this way. However, individual support is offered to families and referrals are made for family therapy if appropriate. Some Icebreak staff have also undertaken specific training in order to support the team's work with parents/significant others in young people's lives. Data show that two-thirds of the service's users do not live with birth families. The University of Plymouth research showed that for many of the Icebreak service users when asked who they saw as significant adults in their lives they said their Care Coordinator. A drop in group with staff facilitation but a loose agenda is in place to enable an informal but safe environment to spend time. A group focused on the redesign of a room on the ground floor of the Zone premises was led by an Icebreak care coordinator in 2006. This enabled them to have a greater feeling of ownership of this space. Young people have participated in the interview processes when recruiting new staff. This is a key part of The Zone's commitment to young people's participation in the agency. Two young people are on the Board of Trustees. One of these accesses Icebreak.

2. Achievements and capacity of the service

The Icebreak offers open, non-stigmatised access to a non-medical service run by staff who empathise with service users. The service receives many referrals from primary care. It also takes referrals from mental health services (about the same number as from primary care) where service users have not been allocated, and does occasionally refer service users to Mental Health services for out of hours support. Icebreak works most closely with Zone colleagues. Staff run groups for various purposes: such as drop-ins, self-harm awareness, friendship groups (non-stigmatised as not exclusively for PD). Groups started in November 2004: and can be accessed by all Zone and Icebreak service users, so that the range of group work available to service users is fairly broad and under constant review, and has included emotional literacy groups (said to be focussed on equipping people for DBT). Comprehensive services (housing advice, sexual health, drug counselling) are available via the Zone. The Icebreak service has also developed a 24/7 telephone support service staffed by care coordinators (although there is no service-led self-help network for service users.)

The service manager states that savings made by the service include those associated with high use of acute admissions, crisis and criminal justice services. The evaluation completed by the University of Plymouth reinforces this view.

3. Departures from original specification: drivers & impediments

Icebreak takes on care coordination. As Icebreak does not adhere to the medical model there is no psychiatrist in post, so the individual GP of the service user remains the RMO. The GPwSI provides input to the team with clinical work and liaises with young peoples GP. The team is multi-disciplinary, and has developed a good level of clinical expertise. There is no focus on 'treatment' per se; rather the focus is on finding ways in which a service user's quality of life and functioning can improve. The proposed capacity of 90 service users (6 workers at 15 each) would impair the delivery of a gold standard service. Specific issues for, and level of support required by, each service user requires some flexibility in the caseload. Therefore, the team aim to work with between 10-15 young people.

4. Areas for future development

The project is an interesting example of tension between the clinical/accountable model favoured by the NHS, and the attempt to engage service users and staff who prefer to work in more flexible ways. The current balance may be susceptible to the demands of changing health commissioners. A particularly strong issue is the need to firm up ways of working with/'treating' (as opposed to assessing and engaging) service users, and the need to address capacity issues, and define move-on motives and strategies. The Life Maps currently being used within Icebreak and The Zone do evidence the gains that young people make whilst accessing the service and the improvements in their lives for the majority of the service users. Some young people have had substantially difficult lives which will take more than the time that this team is able to offer them. However, it would be interesting to see how many young people overtime are able to sustain these changes and make significantly different choices in their lives. As the rationale of this service is to help service users develop ways of coping which prevent their needing future contact with mental health services, a formal evaluation of the capacity of the service to deliver this may be required if it is to become a model that is more widely practiced.

5. Summary of lessons learned by service providers

- Previous experience of working with vulnerable young people and some form of professional qualification are important in identifying new staff for a service for young people with personality-related problems.

- Dedicated services for people with personality-related problems need to have a consistent theoretical model that is used and supported by all front-line workers.

- During the first two years of the project it became apparent that front-line staff assessed service users in a variety of different ways. The development of a standardised assessment process has helped the service develop a more consistent and coordinated approach to working with service users.

- Joint working is important as team members may become more or less busy at different times.

- Endings are difficult for people who have often had previous difficult experiences of loss: a drop-in group provides a means of providing some people with follow-up and continued contact with the service.

6. Summary of service users' views

Six young people were interviewed at the Icebreak service in Plymouth, two men and four women. Interviewees had been in contact with the service for between two and 18 months; they had used the drop-in and one-to-one sessions. Care co-ordinators at this site recruited volunteers and then worked with the service user researchers to set up interviews directly with service users on site. It should be noted that we had little choice about whom we interviewed at this service and were unable to access past service users or carers.

Coming in

These were young people who on arrival at the service had been in a fair amount of chaos and distress and who had already accumulated a fair number of diagnoses between them. In describing their current problems, they talked of eating disorders, depression and suicide, self-harm, psychosis, personality difficulties/disorder, being very frightened, and drug and alcohol problems.

The process of contacting the service and starting to attend had been relatively straightforward and quick for most of the service users. A couple of people had come in through reception at 'The Zone' (Youth Enquiry Service), in which Icebreak is based. Others had been referred or told about the service by a housing association, doctor or other mental health organisation. Several of them talked about having difficulty filling in forms at the start, but most described positive first impressions of the care co-ordinators at their first meeting. The one person who took some time over the process was originally reluctant to attend because she felt as if she had been passed on by her mental health social worker.

Support of the service

The six young people were very positive about the service they were receiving, a service reliant upon the relationship they formed with their care co-ordinator. They had very little to criticise about the service; indeed, one or two said that it had saved their life. All had found the support provided by the care co-ordinators helpful and many had also received help from the out of hours service. A few had received housing and/or benefits advice and very much appreciated these as well. In addition, one or two had received help accessing other services: alcohol services and eating disorders service. One person was unable to access daytime services such as group activities due to being in full time employment.

Relationships with Staff

Nearly all of the young people spoke about their care co-ordinators with some passion, several describing them as 'a lifeline'. A couple of people felt so strongly about this that they said they would not be here today, that they would have killed themselves, if it were not for Icebreak and the support of their care co-ordinator. One person was concerned that he had to get support from people other than his care co-ordinator; ideally he would have liked all of his care and support to come from the same person.

They described their care co-ordinators as reliable and consistent, flexible, non-judgemental, relaxed and friendly, supportive and understanding. It was important that they could be contacted by mobile phone and several mentioned texting as an 'ideal' way of making contact. It seemed that the care co-ordinators could meet the young people on their own terms without judgement and with respect: words such as 'unshockable' and 'not afraid' were used; also: 'He treats me like a person' and 'they up your confidence a lot'.

Out of hours support

Several of the young people had used the out of hours telephone number to access support in a crisis, and found it helpful. For one person, it was the one thing that had stopped her from taking (another) overdose. Others had also found that their care co-ordinator would respond very quickly to a phone call or text when they were in a crisis.

Outcomes

The young people spoke movingly of the ways in which they had changed since coming to Icebreak.

Several talked of a 'massive' change, getting a lot better, or a lot better than I used to be, for example: 'my life is back on track' 'I've got my identity back'. For many, it was learning to talk to their care co-ordinator, finding that there was someone there for them, to listen to them and take them seriously, that had made the difference. One person said that he now talked to his mother more, and another that talking had helped to put things into perspective. Most of the young people talked of gaining confidence, becoming more independent, being more able to stand up to others, and able to go out alone. Several also felt they had learned new ways of dealing with things, such as using drink and drugs less, and talking or picking up the phone instead of self-harming.

Appendix 2

Care Pathway Record and Minimum Dataset

<table>
<tr><td colspan="2">National Evaluation of Personality Disorder Sites
Imperial College, London
CARE PATHWAY RECORD</td></tr>
<tr><td></td><td></td></tr>
<tr><td>Client Research Identifier</td><td>☐☐☐</td></tr>
</table>

SECTION 1: PEOPLE REFERRED TO YOUR SERVICE
(Please complete this section at the <u>earliest opportunity</u> after the clients is referred to the service)

1.1   Date referral received: ☐☐ Day   ☐☐ Month   ☐☐ Year

1.2   Source of referral:

☐ Self   ☐ Family / friend   ☐ Drug service
☐ Community Mental Health Team   ☐ Other LA Social Services   ☐ Probation/prison service
☐ GP   ☐ Housing   ☐ Youth Offending Team
☐ Hospital, psychiatric   ☐ Hospital, General/A&E
☐ Other: *Specify:*_____

1.3   Client's Date of birth: ☐☐ Day   ☐☐ Month   ☐☐ Year

1.4   Sex: ☐ Male   ☐ Female

1.5   Had this person had previous contact (ever) with other mental health services?

☐ No   ☐ Yes   If known, year of most recent contact: _____

1.6   Ethnicity: How does the client describe the ethnic group to which he/she belongs?

Specify, or use one of the categories below:_____

☐ White British   ☐ White Irish   ☐ White other
☐ Black / Black British – Caribbean   ☐ Black / Black British - African   ☐ Black other
☐ Asian / Asian British - Indian   ☐ Asian / Asian British - Pakistani   ☐ Asian / Asian British –
Bangladeshi ☐ Asian / Asian British - Other   ☐ Mixed – White & Black Caribbean   ☐ Mixed – White & Black
African
☐ Mixed – White & Asian   ☐ Chinese   ☐ Not Known

1.7   Presenting problem
Please describe or list very briefly (in note form) the nature of client's principle presenting problem(s).

1.8   Outcome of referral (tick all that apply)

☐ Offered assessment/service ☐ Not offered assessment/service: Reason?_____
☐ Referred, or recommended for referral, to another service: Which? _____
☐ Offered some ongoing support from our service: Nature of support offered? _____
☐ Support/advice given to referrer/referring organisation around management of this client

SECTION 2: FOR THOSE ASSESSED:
(Please complete this section at the <u>earliest opportunity</u> after the clients is assessed by the service)

2.1 The Assessment (tick all that apply)

☐ Person did not attend for assessment

☐ Person attended assessment: When? ☐ Day ☐☐ Month ☐☐ Year

☐ Person found to have PD   ☐ Person thought not to be suffering from PD

☐ Person did NOT meet service criteria: Why? _____

2.2 What was the outcome of the assessment? (tick all that apply)

☐ Offered service   ☐ Put on waiting list for service

☐ Offered limited (not full) support from our service: Nature of support offered? _____

☐ Referred, or recommended for referral, to another service: Which? _____

☐ Not offered any service or referral: Why? _____

SECTION 3: PEOPLE OFFERED A SERVICE
(Please complete this section as information becomes available)

3.1 Client's take-up of the service offered:

☐ Client offered access to main service option

☐ Client offered access to limited/particular services: which? _____

☐ Client started to use service offered: When? ☐☐ Day ☐☐ Month ☐☐ Year

☐ Client offered service, never attended: State why if known _____

3.2 Client's use of service:

☐ Client expected/invited to attend structured sessions ☐ Client free to participate in informal/irregular way

If client expected to attend structured sessions: Number of sessions attended: ☐

Of number of sessions expected: ☐

3.3 Leaving the service

Date of last attendance at service (leave blank
if still attending at end of study) ☐☐ Day ☐☐ Month ☐☐ Year

3.4 Reasons for leaving the service (tick all that apply)

☐ Structured programme complete ☐ Client dropped out of contact ☐ Referred to another service

☐ Admitted to hospital   ☐ Disciplinary reasons   ☐ Moved from area

☐ Sent to prison   ☐ Not known

☐ Other: *Specify:* _____

MINIMUM DATA SET (from all pilot services)

1. We would like to start by asking you about how you *generally are* in **most situations**

In general:	YES	NO
Do you have difficulty making and keeping friends		
Would you normally describe yourself as a loner		
In general, do you have difficulties trusting other people		
Do you normally lose your temper easily		
Are you normally an impulsive sort of person		
Are you normally a worrier		
In general are you a perfectionist		
In general, do you depend on others a lot		
Do you think there is anything about your personality, that is to say the way you generally are, that needs to be changed		

2. We would now like to ask your use of other services in the **SIX MONTHS BEFORE YOU STARTED TO USE THE HAVEN.** **If this is hard to remember, perhaps you could guess!** In the six months before you started to use the HAVEN, how often ...

	NO	Once	2 or 3 times	More than 3 times
Did you see your GP?				
Did you have to make an **emergency appointment** to see your GP?				
Did you attend an Accident and Emergency department?				
Did you have an admission to hospital?				
Have you seen a social worker, benefits or housing worker?				
Did you have contact with the police?				
Were you arrested?				
Were you charged with an offence?				

3. Please consider the statements below and for each one, please tell us the response which best fits your experience during the last **six months**.

I complete my tasks at work and home satisfactorily

Most of the time	
Quite often	
Sometimes	
Not at all	

I find my tasks at work and at home very stressful

Most of the time	
Quite often	
Sometimes	
Not at all	

I have no money problems

No problems at all	
Slight worries only	
Definite problems	
Very severe problems	

I have difficulties in getting and keeping close relationships	Severe difficulties	
	Some problems	
	Occasional problems	
	No problems at all	

I have problems in my sex life	Severe difficulties	
	Moderate problems	
	Occasional problems	
	No problems at all	

I get on well with my family and other relatives	Yes, definitely	
	Yes, usually	
	No, some problems	
	No, severe problems	

I feel lonely and isolated from other people	Almost all the time	
	Much of the time	
	Not usually	
	Not at all	

I enjoy my spare time	Very much	
	Sometimes	
	Not often	
	Not at all	

I generally have difficulties getting on with people	Very much	
	Sometimes	
	Not often	
	Not at all	

Appendix 3

Delphi Survey

1. ORGANISATION OF SERVICES FOR PEOPLE WITH PD: *We would like to start by asking you for your views on the way that services for people with PD should be organised. In this section we would like you to consider* <u>services for people with PD in general</u>

1.1   Most people with PD do NOT require dedicated services to help them cope with their problems

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	**agree**

1.2   If providers of general health and social care were trained and financially supported to deliver services for people with PD, dedicated services would not be required

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	**agree**

1.3   Setting up dedicated PD services reduces the capacity of general services to help people with PD

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	**agree**

1.4   PD services are best sited in different premises to other mental health services

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	**agree**

1.5   Dedicated services for people with PD based in the voluntary sector are needed as well as those in the statutory sector

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	**agree**

1.6   People with PD who are dependent on alcohol or other drugs are unable to make use of psychological treatments

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	**agree**

1.7   Dedicated community-based PD services should not be expected to work with people who have a history of violent offending

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	**agree**

1.8   Dedicated services should use assertive outreach in order to work with people with severe PD who do not feel that they need help with their problems

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	**agree**

1.9   There are circumstances when it is appropriate to use the Mental Health Act to compel (force) a person to attend community-based services for treatment of personality disorder

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	**agree**

1.10   Dedicated PD teams should provide services for people who have PD and sometimes hear voices or experience other psychotic symptoms

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	**agree**

1.11   Dedicated PD services should focus on people who are high users of inpatient and emergency services

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	**agree**

1.12   Dedicated PD services should be open to self-referral and referral by concerned friends/ relatives

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	**agree**

1.13   When mental health services refer someone to a dedicated PD service it is important for a member of the referring team to remain in regular contact with them

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	**agree**

2. DELIVERING SERVICES TO PEOPLE WITH PD: *In this section we would like you to consider services delivered by a dedicated team providing community based treatment for people with PD*

2.1   Dedicated services for people with PD should focus on providing treatments or therapies that service users want

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	**agree**

2.2   Evidence from research studies about 'what works' for people with PD is too limited to guide service delivery

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	**agree**

2.3   Interventions aimed at helping people with PD develop better coping strategies need be delivered over years not months

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	**agree**

2.4   Services for people with PD should provide care coordination under the 'care programme approach' (CPA)

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	**agree**

2.5   Care plans with short and long-term treatment goals agreed by the client are important if progress in treatment is to be both achieved and recognised

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	**agree**

2.6   It does not matter if PD services do not have a clear treatment model, as long as there are demonstrable positive outcomes for service users and others

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	**agree**

2.7   Dedicated services for people with PD should be able to arrange more intensive support at times of crisis such as home treatment or residential care

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	**agree**

2.8   Limits on the availability of staff and other boundaries need to be made clear to service users at the start of treatment and stuck to throughout treatment

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	**agree**

2.9   Responsibility for client welfare should be shared by a team and/or the community, rather than by individual staff members

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	**agree**

2.10   Group work is more productive for people with PD than individual one-to-one work

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	**agree**

2.11   Some PD clients cannot cope with groups or environments where people have to interact

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	**agree**

2.12 Dedicated PD services should provide service users some form of access to their own staff 24 hours a day

	1	2	3	4	5	6	7	8	9	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	agree

2.13 Risk management for people with PD involves placing a high degree of choice and responsibility with the person who is harming her/ himself

	1	2	3	4	5	6	7	8	9	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	agree

2.14 In-patient treatment on a mental health unit is unlikely to be therapeutic for people with PD

	1	2	3	4	5	6	7	8	9	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	agree

2.15 Services for people with PD should try to obtain users' consent to contact, support and inform carers

	1	2	3	4	5	6	7	8	9	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	agree

2.16 Information about services for people with PD should always use the term 'personality disorder

	1	2	3	4	5	6	7	8	9	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	agree

2.17 Services for people with PD should define their client groups by sets of symptoms/ behaviours rather than by formal diagnoses

	1	2	3	4	5	6	7	8	9	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	agree

2.18 Users and their carers should be involved in making decisions about service development

	1	2	3	4	5	6	7	8	9	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	agree

2.19 Services for people with a diagnosis of PD should encourage users to decide the frequency of their contact with the service

	1	2	3	4	5	6	7	8	9	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	agree

3. STAFFING ISSUES: *In this section we would like you to consider staff who work with people with PD and teams of people involved in providing PD services*

3.1 The personal qualities of staff – such as self-awareness and ability to observe boundaries – are more relevant to working well with PD clients than professional qualifications

	1	2	3	4	5	6	7	8	9	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	agree

3.2 Teams delivering services to people with PD need to consist of people with a range of professional and non-professional backgrounds

	1	2	3	4	5	6	7	8	9	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	agree

3.3 Teams delivering services for people with PD should have regular input from a social worker

	1	2	3	4	5	6	7	8	9	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	agree

3.4 Teams delivering services for people with PD should have regular input from a psychiatrist

	1	2	3	4	5	6	7	8	9	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	agree

3.5 Teams delivering services for people with PD should have regular input from an 'expert by experience' (a service user worker)

	1	2	3	4	5	6	7	8	9	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	agree

3.6   It is essential for staff of PD services to have a forum to come together to reflect on their practice, their relationships with clients and the impact their work has on team members

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	**agree**

3.7   It is more useful for dedicated PD services to train and support general health and social care services to manage difficult PD clients than it is for them to directly manage those clients

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	**agree**

3.8   Training in this field should ideally be given to teams, rather than individuals

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	**agree**

3.9   Consultation around specific individual cases and events encountered in practice is more useful than generalised training around PD assessment and management

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	**agree**

4. USER INVOLVEMENT AND PEER SUPPORT: *In this section we would like you to consider arrangements through which service users are directly involved in providing peer support and services for other users*

4.1   Services which bring clients together in an environment where they can offer mutual support are ultimately more valuable than services that rely on client-professional interaction

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	**agree**

4.2   Sanctions (such as time away from a service) imposed and reinforced by peers (rather than staff) are seen by clients as fairer and less personally discriminating than those imposed by staff

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	**agree**

4.3   Service users should be encouraged and supported to run out-of-hours crisis support

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	**agree**

4.4   Service users who provide peer-support should use their own judgement when making decisions about whether or not issues raised by service users should be brought back to supervision

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	**agree**

4.5   It is always desirable that groups of service users in therapy should be facilitated by trained staff

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	**agree**

4.6   All people with PD should have access to user-led services

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	**agree**

4.7   The development of service user-led services is necessarily slower than those provided by professional staff

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	**agree**

4.8   Participation in 'user-involvement' activities helps a person with PD sustain their recovery

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	
disagree	☐	☐	☐	☐	☐	☐	☐	☐	☐	**agree**

5. PRIORITES FOR SERVICE DEVELOPMENT: *We would like you to imagine an area where currently there are* **NO dedicated PD services**. *Using the scales below, which go from 1 (should not be provided), through to 9 (the HIGHEST priority), please tick the box that reflects how great a priority you feel should be given to each of the following types of service development for people with PD.*

5.1 Organisational change and service developments to ensure that existing (non-specialist) services have the capacity to provide high quality care to people with PD

1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
☐	☐	☐	☐	☐	☐	☐	☐	☐

Should not be provided   **low priority**   **a priority**   **high priority**   **HIGHEST priority**

5.2 A community-based service providing psychological treatments e.g. DBT, CBT or psychotherapy

1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
☐	☐	☐	☐	☐	☐	☐	☐	☐

Should not be provided   **low priority**   **a priority**   **high priority**   **HIGHEST priority**

5.3 An inpatient unit to provide intensive treatment for people with severe PD

1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
☐	☐	☐	☐	☐	☐	☐	☐	☐

Should not be provided   **low priority**   **a priority**   **high priority**   **HIGHEST priority**

5.4 A service user network to provide peer-support for service users by service users

1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
☐	☐	☐	☐	☐	☐	☐	☐	☐

Should not be provided   **low priority**   **a priority**   **high priority**   **HIGHEST priority**

5.5 A consultation service providing expert guidance to those working in health and social care to support their work with people with PD

1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
☐	☐	☐	☐	☐	☐	☐	☐	☐

Should not be provided   **low priority**   **a priority**   **high priority**   **HIGHEST priority**

5.6 A dedicated day service providing individual and group based treatments

1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
☐	☐	☐	☐	☐	☐	☐	☐	☐

Should not be provided   **low priority**   **a priority**   **high priority**   **HIGHEST priority**

5.7 A dedicated community team which takes on case management and care planning for people with PD

1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
☐	☐	☐	☐	☐	☐	☐	☐	☐

Should not be provided   **low priority**   **a priority**   **high priority**   **HIGHEST priority**

5.8 A therapeutic community

1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
☐	☐	☐	☐	☐	☐	☐	☐	☐

Should not be provided   **low priority**   **a priority**   **high priority**   **HIGHEST priority**

5.9 Deployment of dedicated PD workers working within existing community mental health teams

1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
☐	☐	☐	☐	☐	☐	☐	☐	☐

Should not be provided   **low priority**   **a priority**   **high priority**   **HIGHEST priority**

5.10 Training and support to enable people back into employment

1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
☐	☐	☐	☐	☐	☐	☐	☐	☐

Should not be provided   **low priority**   **a priority**   **high priority**   **HIGHEST priority**

5.11 A service which aims to reduce stigma and discrimination associated with a diagnosis of PD

1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
☐	☐	☐	☐	☐	☐	☐	☐	☐

6. EXAMINING SERVICE OUTCOMES

Dedicated services for people with PD usually try to help a person achieve a range of goals. However, when efforts are made to evaluate the impact of services for people with PD what measure do you think is most important to assess?

6.1   Reductions in symptoms of anxiety, depression and mental distress to normal levels

1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
☐	☐	☐	☐	☐	☐	☐	☐	☐
Unimportant		**not very important**		**important**		**very important**		**the MOST important**

6.2   Improved social functioning (e.g. so people can sustain long- term relationships in their work and personal life)

1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
☐	☐	☐	☐	☐	☐	☐	☐	☐
Unimportant		**not very important**		**important**		**very important**		**the MOST important**

6.3   Reduced levels of use of inpatient care and contacts with emergency medical services

1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
☐	☐	☐	☐	☐	☐	☐	☐	☐
Unimportant		**not very important**		**important**		**very important**		**the MOST important**

6.4   Improved quality of life (a person's level of comfort, enjoyment, & ability to pursue daily activities) to normal levels

1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
☐	☐	☐	☐	☐	☐	☐	☐	☐
Unimportant		**not very important**		**important**		**very important**		**the MOST important**

6.5   Reductions in impulsive behavior so that self-harming, aggression and/ or violence stops

1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
☐	☐	☐	☐	☐	☐	☐	☐	☐
Unimportant		**not very important**		**important**		**very important**		**the MOST important**

6.6   User-rated satisfaction with service quality

1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
☐	☐	☐	☐	☐	☐	☐	☐	☐
Unimportant		**not very important**		**important**		**very important**		**the MOST important**

6.7   None of the above (please add your suggestion for what should be measured below)

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7. COMMENTS AND OTHER ISSUES YOU WOULD LIKE US TO INCLUDE IN THE NEXT SURVEY

Finally we would be grateful if you could add any topic you think we should have included in this survey in the space below. If the item(s) you raise are supported by others we will endeavour to include these in the next wave of survey. Please also feel free to add any additional comments you have about this survey here.

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Thank you for your time and support

Appendix 4 Items reaching consensus level in at least one of the three stakeholder groups

Expert authors	Service providers	Service users
Most people with PD do NOT require dedicated services	-	**Most people with PD do NOT require dedicated services**
If providers of general services were properly supported dedicated PD services would not be required	-	-
Dedicated PD services should focus on people who are high users of inpatient and emergency services	Dedicated PD teams should work with people who sometimes experience psychotic symptoms	Dedicated PD teams should work with people who sometimes experience psychotic symptoms
Dedicated PD services should be open to self-referral	-	Dedicated PD services should be open to self-referral
Following referral, a member of the referring team should remain in regular contact with the person	Following referral, a member of the referring team should remain in regular contact with the person	Following referral, a member of the referring team should remain in regular contact with the person
It is unacceptable for CMHTs to have a policy of not working with people with a primary diagnosis of PD	It is unacceptable for CMHTs to have a policy of not working with people with PD	It is unacceptable for CMHTs to have a policy of not working with people with PD
-	Interventions need be delivered over years not months	Interventions need be delivered over years not months
Services for people with PD should provide care coordination under the 'care programme approach'	-	Services for people with PD should provide care coordination under the 'care programme approach'
Care plans with short and long-term treatment goals agreed by the client are important	Care plans with short and long-term treatment goals agreed by the client are important	Care plans with short and long-term treatment goals agreed by the client are important
Services should be able to arrange home treatment or residential care at times of crisis	Services should be able to arrange home treatment or residential care at times of crisis	Services should be able to arrange home treatment or residential care at times of crisis
Boundaries need to be made clear at the start and stuck to throughout treatment	Boundaries need to be made clear at the start and stuck to throughout treatment	Boundaries need to be made clear at the start and stuck to throughout treatment
Responsibility for client should be shared by a team and/or the community, rather than by individual staff members	Responsibility for client should be shared by a team and/or the community, rather than by individual staff members	-
-	Some PD clients cannot cope with groups or environments where people have to interact	Some PD clients cannot cope with groups or environments where people have to interact
Risk management involves placing a high degree of responsibility with the person who is harming her/himself	Risk management involves placing a high degree of responsibility with the person who is harming her/himself	-
Services should try to obtain users' consent to contact, support and inform carers	Services should try to obtain users' consent to contact, support and inform carers	Services should try to obtain users' consent to contact, support and inform carers

Expert authors	Service providers	Service users
Users and their carers should be involved in making decisions about service development	Users and their carers should be involved in making decisions about service development	Users and their carers should be involved in making decisions about service development
Services for people with a diagnosis of PD should encourage users to decide the frequency of their contact with the service	-	-
Personal qualities of staff are more relevant than professional qualifications	Personal qualities of staff are more relevant than professional qualifications	Personal qualities of staff are more relevant than professional qualifications
Teams need to consist of people with a range of professional and non-professional backgrounds	Teams need to consist of people with a range of professional and non-professional backgrounds	Teams need to consist of people with a range of professional and non-professional backgrounds
-	Teams should have regular input from an 'expert by experience' (a service user worker)	Teams should have regular input from an 'expert by experience' (a service user worker)
It is essential for staff to have a forum to come together to reflect on their practice	It is essential for staff to have a forum to come together to reflect on their practice	It is essential for staff to have a forum to come together to reflect on their practice
It is more useful to train and support general services to manage difficult PD clients than it is to directly manage them	-	-
Training in this field should ideally be given to teams, rather than individuals	Training in this field should ideally be given to teams, rather than individuals	Training in this field should ideally be given to teams, rather than individuals
-	Service users are able to successfully run groups for people with PD as long as they are provided with training and support	
-	Participation in 'user-involvement' activities helps a person with PD sustain their recovery	-
-	-	People with PD should be employed to deliver direct service provision to other service users.

Note: Statements have been abbreviated. Please see appendix C for a more complete versions of most of the statements we used.
Items in bold are those where the consensus was that the statement was opposed (in the range 1 to 3).
* These two items were the only ones where consensus was in the 'neutral' range (4 to 6).