

# Partnership and Complexity in Continuity of Care: a study of vertical and horizontal integration across organisational and professional boundaries

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

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## ***Executive Summary***

This is the research report of the study of partnership and complexity in continuity of care. It is a detailed report of continuity of care in two conditions, namely older people who have had a stroke (55 years of age and over) and young people with a learning disability. The study was conducted in three localities, selected to represent a spectrum of inter-organisational complexity and histories of joint working. The three localities were Darlington, South Tyneside and Lancashire.

We focused mainly but not exclusively on two 'hinge points' where, in each condition, we would be able to test for discontinuities at significant inter-organisational and inter-professional boundaries. In the case of stroke this hinge point was the transition from hospital to home at the point of discharge. In the case of learning disability it was the transition for young people leaving school and entering adulthood. We employed a range of qualitative methods, including documentary analysis, non-participant observation and a substantial number of in-depth and face-to-face interviews with service professionals and managers and with patients/users and their carers.

The severe organisational turbulence during the study, particularly in the NHS, when combined with a multiplicity of overlapping organisational boundaries, impedes rather than promotes continuity of care. On the other hand, conterminosity and relative environmental stability are solid foundations for, but not guarantees of, joined-up service delivery. The South Tyneside stroke service prospered in this respect.

Many of the contextual factors that hinder continuity of care are structural in nature. Key clinical roles such as clinical psychology in stroke services, which official guidance makes clear are important, were simply not present (with the exception of South Tyneside). In both conditions there were problems associated with shortages of allied health professionals. These are particular illustrations of long-standing problems associated with investments in service development in these two conditions. It was also suggested that this historic under-funding reflects national priorities.

We found evidence that long-standing issues, such as the divide between health and social care, continue to hamper continuity of service delivery on the ground. In the case of learning disability the most pronounced discontinuity was evident at the boundary between social care and education services.

Continuity of care, together with its synonyms seamless care and integrated care, is part of the current lexicon of joined-up government and whole-system working. As experienced by patients and service users, continuity of care should be the operational expression of joined-up government, as experienced by service users. If it reflects the rhetoric of whole-system working and patient-centred care, then it should span all of an individual's experiences of care and support in all settings.

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In stroke services we did find examples of continuity of care which reflected organisations and service professionals working across boundaries. In the case of learning disability services we found much of the machinery and tools of partnership working but little evidence of this producing continuity of care for individual service users. Our overall conclusion was that the transition from school for young people with a learning disability was characterised by discontinuity rather than continuity of care. This was evident in two respects. First, it was evident in the abrupt shift from children's services to adult social care. Second, and just as marked, it was found in the transition from paediatric to adult health services. Services that had formerly been readily available and free were now charged for and often unavailable. We found that abrupt service deficits arising from chronologically based eligibility criteria were a constant source of distress. Strikingly, even though the transition from school was predictable, it appeared to users and their carers to be poorly planned and poorly co-ordinated.

In the case of stroke services, we found evidence of perceived discontinuities of care in, for example, transfers between wards and between hospitals. However, several of the recruited patients reported experiences of treatment, rehabilitation and care which to them and their carers appeared both well planned and well co-ordinated.

In both conditions, however, the limited duration of any such joined-up working was an issue. Viewed from the perspective of the service user, continuity of care should be just that – continuous – and should extend beyond and outside any one formally approved care pathway. Continuity is about the organisation of care in general, and not about continuity within any one episode. In the case of learning disability services, one of the main concerns of carers was not with the transition from school to college, but the subsequent transition from college to employment and independent living. In the case of stroke services, patients and their carers were keen to be reassured that care and support would not be 'turned off', even at the point where formal care and support had ceased.

Indeed, the study's main conceptual insight is that the term continuity of care is most meaningful when viewed from the perspective of the service user. It is the service user who has the continuous – or discontinuous – experience. There is no other group of people or sequence of events whose actions or experiences are in any sense continuous. Service providers come and go, and there is no consistent pattern of communication and feedback between any of the other parties involved in treatment and care.

Care pathways are a convenient fiction. They are often characterised in National Service Frameworks and other documents as linear sequences of events. The experiences of service users reported in this study suggest that there are indeed fairly predictable sequences of events, which are common across most of the people we worked with.

Equally, though, there was strong evidence demonstrating the diversity of people's experiences in both services, and also evidence, particularly in stroke care, of the numbers of decisions that are made about treatment and care. This diversity is not simply unwanted variation – although it is partly that – but evidence of service-delivery systems that are, however imperfectly at times, responding to service users as individuals.



# ***The Report***

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## **Section 1 Introduction**

The National Co-ordinating Centre for NHS Service Delivery and Organisation R&D (SDO Programme) commissioned a number of research projects on the general theme of continuity of care. This study, which started in January 2002 and finished in April 2005, was designed to explore the ways in which new Government policies on partnership working were affecting the continuity of care delivered on the ground. In particular, the study aimed to understand the ways in which continuity of care was affected by the complexity of inter-organisational arrangements and the complexity of inter-professional working arrangements. It also aimed to explore the relationship between inter-organisational and inter-professional complexity.

The research was undertaken in three sites, namely Darlington, Lancashire and South Tyneside, in respect of two 'tracer' conditions: stroke care and the care of younger people with learning disabilities who are making the transition to adulthood.

The report has five main sections. Section 2 sets out the research design and methods that were used in this study. Fundamentally, this was a study of the perceptions and experiences of care as viewed by service users and their families and carers, and as viewed by service providers and local managers. Section 3 sets out the general policy context within which continuity of care has been promoted over the last few years. Sections 4 and 5 contain the main empirical results of the study. Section 4 sets out the policy context for stroke, and reports on the experiences and views of all of the parties involved in the delivery of services to people who have had strokes. Section 5, similarly, presents the policy context within which services for people with learning disabilities have developed, and our evidence about the experiences of the parties involved in services. Section 6 summarises our results, identifying the factors that promote and inhibit continuity of care, and sets the results in a wider organisational and policy context.

## Section 2 Research design and methodology

### **2.1 Introduction**

This study involves a detailed examination of continuity of care, as experienced by patients/users and their families and carers, and as perceived by relevant care professionals and managers and the wider clinical and managerial communities. This section outlines the research design and methodological approaches used to explore such service outcomes and processes, and to capture the range of factors impacting upon them.

Our research was initially designed as a study of the role of inter-professional and inter-organisational co-ordination in continuity of care. From the outset the issues seemed inherently complex in two senses, namely that they involved dealing with uncertainty, and that they had many interacting elements. Diagnosis, treatment and care involve many people co-ordinating their work at any one point in time, and through time. Here, we were interested in what happens at inter-professional boundaries, and our initial hypothesis was that continuity of care would be more likely in a predictable condition in which there are relatively few professions involved, and where there is consensus between professionals about the best treatment and care. We were also interested in inter-organisational issues. We were anticipating that, *ceteris paribus*, continuity of care would be more likely in local health and social care systems where there are fewer organisational boundaries to be traversed, and a history of joint working at strategic and operational levels. Here, we were contending, the conditions for delivering continuity of care would be inherently more favourable.

This focus gave us the main theoretical context for the study, which by its nature would be a study of partnership arrangements of various kinds, and hence more generally of the co-ordination of services (Hood, 1998, 2005). There is a substantial literature on partnerships, including partnerships in health and social care, that we draw upon in this report. Equally, recent trends in Government policies have placed considerable emphasis on 'joined-up' and 'whole systems' working, and it was not clear at the start of the study how far these were essentially a re-working of older policies or had some genuinely novel features. Therefore, to some extent the study was an investigation of co-ordination of care in the new policy environment. The policy context is discussed in Section 3.

### **2.2 The selection of stroke and learning disability as tracer conditions for the case study**

The two tracer conditions were as follows.

- 1 People who have had a severe stroke. We initially intended to focus on people aged 65 and over but following advice from fieldwork sites subsequently included patients aged 55 years and over.

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- 2 Young people with a learning disability making the transition from childhood to young adulthood.

There were a number of reasons why learning disability and stroke were selected. In the case of learning disability we were selecting a condition which we (initially) thought would be relatively straightforward in terms of the range of organisations and professions – and hence boundary disputes and discontinuities – potentially involved. This was not a service involving ‘simple partnerships’, but learning disability was felt to be a condition with some degree of predictability and consensus regarding diagnosis, treatment and prognosis. Young people will also have been in the system for several years prior to transition and this too reduces uncertainty. Finally, the dominant paradigm in learning disability is the so-called social model, and it is common practice for local councils to assume leadership on Learning Disability Partnership Boards. Conversely, the range of partners involved in transition is substantial, including health, social care, local education authorities, children’s services, Connexions, Learning and Skills Councils (LSCs), the Workstep Programme, Job Brokers in the New Deal for Disabled People and the Benefits Agency, among many others. Councils have had to engage new organisational partners in service planning and development. The Department of Health (2001a, para 9) recognised that the early innovative record on partnership working in this field was neither widespread nor had it been sustained. This complexity within the learning disability case study was confirmed during subsequent fieldwork, as detailed in Section 5.

Stroke was selected because it is complex in both senses, namely that it involves uncertainty and services with many elements that need to be co-ordinated. The organisational and partnership arrangements have fewer historical roots than in learning disability services. Standard Five of the National Service Framework (NSF) for Older People (Department of Health, 2001b), which covers stroke, for example, emphasises the need for the NHS to work in partnership much more effectively with other agencies. As the NSF noted: ‘care provided on the basis of assessment may well not be co-ordinated or follow the complex care pathway an older person might follow’ (para 2.3). In addition, we were aware that there is scant published material relevant to continuity of care in stroke, a fact confirmed by the literature review undertaken as part of our study (see Appendix 1). By focusing upon the relationship between specialist stroke services providing acute care and rehabilitation, and long-term support for stroke patients and their carers, we would therefore encompass inter-organisational and inter-professional complexities in continuity of care.

### ***2.3 The selection of sites for exploring the case-study conditions***

Three sites were selected for our studies of stroke and learning disability care pathways, to reflect a range in the number of statutory authorities responsible for health and social care. The three sites chosen were Darlington, South Tyneside and Lancashire.

In the most simple – South Tyneside – the single unitary authority (responsible among other things, for both social services and housing) was conterminous with a single primary care trust (PCT; after April 2002). In

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Darlington there was a single, unitary authority conterminous with a single PCT but relating – as one of six PCTs – to the new county-wide NHS Trust, created in October 2002. The third site selected for case studies, Lancashire, was selected precisely because of its complexity in these dimensions. Lancashire County Council covers a total of 11 districts (and Preston City Council) that each have responsibility, among other things, for the provision of housing and home adaptations in their areas. The county council (as social service authority) also provides a Welfare Rights Service from a total of six bases serving between one and three districts. In the NHS, there are four Acute Trusts based in Preston, Clitheroe, Burnley and Morecambe Bay and a total of eight PCTs that work either completely or partly within the area covered by Lancashire County Council. The PCT boundaries (after the April 2002 re-organisation of county council services that coincided with the transition of Primary Care Group to PCT status) mainly correspond to local-authority districts (ranging from a single district to a combination of three) in terms of their geographical coverage. However, one, Morecambe Bay PCT, straddles the boundary of Lancashire and Cumbria counties. Similarly, Morecambe Bay Hospitals Trust covers sites in Cumbria in addition to its Lancaster hospital site within Lancashire. Lancashire County also relates (in relation to the planning and provision of services at its borders) to two unitary authorities in Blackpool, and Blackburn with Darwin – both of which have additional, conterminous PCTs, and an NHS Acute Trust either based within the unitary authority (in the case of Blackpool) or crossing the border with a Lancashire district (in the case of East Lancashire Hospitals Trust which has sites in both Burnley and Blackburn). The single Lancashire-wide Ambulance Trust is responsible for services provided from local bases across Lancashire County and the two unitary authorities. There is also a single mental health trust, Lancashire Care Trust (with its headquarters in Preston) that has responsibility across the entire area of Lancashire, Blackpool and Blackburn with Darwin.

It was agreed at the outset that we would, in Lancashire, focus on particular localities for both tracer conditions. On the basis of discussions with local service managers and service professionals, these localities were selected to capture the complexity of service planning and delivery across Lancashire. The specific area chosen for the learning disability element of the study was Chorley and South Ribble. This was the area where the Transitions Coordinator for learning disability had been in post the longest and partnership mechanisms (Partnership Board, integrated commissioning arrangements including a pooled budget for adult services) were most fully established. Service managers felt, therefore, that Chorley and South Ribble provided the best environment within the county both for our research and, as a corollary, for their own organisational learning in relation to transition. The areas chosen for the stroke service element of the project were the Fylde and Wyre Districts. They provided the added complexity that the main NHS Acute Trust provider operates across the county border within the unitary authority of Blackpool. In addition, Fylde and Wyre local-authority services relate to a further two Acute hospitals in Lancaster and Preston. In other words – of our three sites used for the case studies of stroke and learning disability as tracer conditions – Lancashire (and Fylde and Wyre in particular) provided the context in which there were most opportunities for discontinuity

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because of the huge range of overlapping professional and organisational boundaries present.

In the context of site selection for the case studies, it is important to note that our original intention was to select four sites covering more and less institutionally complex local areas – i.e. conterminous PCT and single-purpose local-authority versus non-conterminous PCT and many-purpose local authority – with examples of good and poor histories and culture of joint working represented across both types. Due to delays associated with obtaining ethics and local Research Governance approval (despite submission of relevant applications at the earliest possible stage of the research process), however, it proved necessary to focus our efforts on the three localities described above. In the event, we do not feel that this detracted from our ability explore continuity of care in an appropriate range of contexts.

### ***2.4 Outline of research methods***

We used the case-study method (Ragin, 2000), and a form of critical case sampling to select our patient/user cases (Patton, 1997), to identify and understand continuities and discontinuities of care. This approach permits logical generalisation and maximum application of findings to other cases. We also used triangulation of data and methods within our case studies to generate the ‘thickest’ possible descriptions (Geertz, 1973) of processes over time from the perspectives of those principally involved.

The study was undertaken over a 3-year period between 2002 and 2005, and had three discrete elements:

- 1 initial literature reviews relating to continuity in both stroke and learning disability services;
- 2 the use of consensus-development techniques to confirm and, if necessary, modify the literature review findings;
- 3 field research at three sites; the principal methods used were interviews with service providers, longitudinal tracking of service users and their carers, and non-participant observation of meetings concerning care processes.

#### ***2.4.1 Literature reviews***

The first element of the research involved the production of two literature reviews focusing on our selected services (stroke and learning disability) and the organisational factors that influence continuity of care in relation to them. The reviews focused primarily on UK literature (including clinical guidelines), but incorporated international evidence where it was judged relevant to UK practice. The reviews began the process of (a) identifying judgement criteria for continuity and discontinuity of care, (b) distinguishing between what might be seen as appropriate and inappropriate continuities and discontinuities and (c) establishing the location of key ‘hinge points’ in services, and hence key inter-professional and inter-organisational boundaries. The methods used in the reviews are set out in detail in Appendix 1. The findings of the literature reviews are incorporated in Sections 4 and 5 of the report, which also present our main fieldwork findings in relation to each service. In the case of learning

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disability the revised literature review has also been used as the basis for publications (Hudson, 2003a, 2003b).

### **2.4.2 Consensus-development groups**

The initial literature review findings were discussed at meetings of our stroke and learning disability consensus-development groups, which consisted of representatives of service users and carers, and service providers, identified via relevant bodies such as Royal Colleges, Association of Directors of Social Services, NHS Confederation, Stroke Association and Value Into Action. The reviews were amended in the light of comments made at the meetings. The groups were also asked for their opinions on site selection, thereby supplementing our consultations with other bodies on that subject.

The main purpose of convening the consensus-development groups, though, was to help us to create initial, normative descriptions of the hinge processes in each pathway that could subsequently be investigated in the fieldwork. We suspected, and the literature reviews confirmed, that there was limited evidence about the care processes at any potential hinge points, even obvious ones such as leaving hospital following a stroke. We followed the general precepts of consensus-development methods (Jones and Hunter, 2000), although it would be more accurate to describe the events as valuable meetings with groups of experts – using the term expert broadly – than as the use of a structured method with a defined analytical strategy associated with it. One group was convened for each of the two conditions, and in the course of the meetings members were asked to identify hinge points, the key points in the journeys of service users and carers through services. They were asked for their perceptions of the organisation of services at these points, how well they worked in practice and the origins of any problems that they identified, such as poor communications between professionals.

### **2.4.3 Fieldwork**

The main part of the study involved 2 years of fieldwork in which, for each tracer condition, the normative descriptions of appropriate continuity of care established in stages 1 and 2 were tested out in our case-study sites using a range of qualitative data-collection techniques. The interviews throughout the study were in-depth and semi-structured (Pawson and Tilley, 1997, Chapter 6; Ragin, 2000; Silverman, 2004). The policy context, which informed the approach to the interviews, is set out in Section 3. The schedules used for all interviews are in Appendix 2. All of the interviews were tape-recorded with participants' permission. They were subsequently transcribed in full and analysed, together with qualitative data from field notes of meeting observations and case-note and document analysis, using rigorous thematic coding techniques (see Dey, 1993).

In relation to learning disability services, a first round of about 50 interviews was undertaken across our three case-study sites during the first half of 2003. The interviews covered a cross section of managers and professionals dealing with both children's and adult services (i.e. Transition Co-ordinator, social services managers and front-line social workers, PCT and community health managers and front-line workers, Connexions, the Local Education Authority (LEA) and special schools, Employment and Day Services), and a total of 14

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young people (identified and contacted first by social services staff in order to gain permission for researchers to contact them). In the latter case, the interviews were conducted with service users themselves and parents or other carers as appropriate. In addition, social services staff provided the names of four other young people. We were unable to make contact with them, following several attempts to do so.

A second complete round of interviews took place in late 2004 (covering 18 of the most key managers and professionals and the parents across our three sites. These second round interviews, in addition to capturing relevant perceptions of services, reflected the changing nature of organisational structures in our sites, for example, covering managers employed by newly established Children's Trusts as well as repeating interviews with staff interviewed in round one.

The purpose of the interviews with young people and their carers, in addition to beginning the evidence-gathering process, was to explain our study to them, and to obtain their formal, written consent to participate in the study. This allowed us to undertake a key part of the study, namely the tracking of these people over time, in order that we could establish in detail what happened to them at the hinge points we had identified as (likely to be) important, and to capture their perceptions of the quality of care at those points.

Younger people were selected for inclusion in the study on the basis of the criteria summarised in Box 1. The intention was to cover and track young people (and their families) who had reached a range of different points in the transition process. It proved not to be appropriate, as had been the original intention, to track a single age cohort of users over a 12-month period before and after the school-leaving element of transition that takes place at ages 18–19. We found that the entire process of transition takes many years, and can continue until young people are well into their 20s and are leaving college. We therefore chose to track a group of young people spanning a wider age range (from 16 to early 20s), thereby gaining a broader insight into experiences at different stages of the transition.

### ***Box 1 Inclusion criteria for learning disability service users***

In each of the three sites, the aim (though it did not subsequently prove possible for social work care managers to identify this number of young people) was to undertake interviews/gain access to case notes in relation to:

- a three young people coming up to school-leaving age at 16, 17 or 18/19 – i.e. currently going through transition;
- b three young people who have gone through transition – for example, they were at college or were in employment etc.
- c three young people who have, for example, been to college and come out of the transition process altogether.

In addition, the intention was, insofar as it was possible for social workers to identify young people fitting the criteria, within (a), (b) and (c) above, to cover approximately three complex cases, three cases of young people who were statemented, and three cases of young people with less complex needs who have no statement.

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In relation to stroke, a total of 52 managers (in the Acute and community hospitals, PCT and social services) and professional staff (doctors, the stroke specialist nurse/stroke co-ordinator and other nurses, physiotherapists, occupational therapists, speech and language therapists, dieticians and clinical psychologists) were interviewed in the first round of the study. Six of these were also followed-up for a second interview, but due to the delays in access described above repeat interviews were not appropriate in our third site.

A total of 18 patients and family members were recruited to the study from the stroke specialist wards across our three sites and tracked through the local health and social care system for up to 9 months. That is, they were tracked until approximately 2–3 months after their move to either their own home or residential or nursing care. (See Appendix 2 for relevant interview schedules for managers/professionals and patients/carers.) There were five cases in one site, six in another and seven in the third, with five 'active' cases across the three sites at any one time. During the fieldwork there was a need to replace one patient who died and one who withdrew from the study, and they were not included in the analysis.

### ***Box 2 Inclusion criteria for stroke patients***

Number: five active cases in each locality over the duration of the fieldwork

Age: 55+

Gender: three female:two male

Start: 7 days after admission to acute care

End: indeterminate; when there is consensus, between patient, carer, care professionals and researchers about stability in terms of condition and care.

Condition: two-dimensional. One of each of the possible combinations between co-morbidity (none or significant) and severity of stroke (low and high). The fifth case depending on local circumstances.

Measure of severity:

Low – person who, at 7 days, is expected to return home without need for long-term residential (or nursing care) or domiciliary care.

High – person who, at 7 days, is expected to need help upon discharge with transfer and walking.

Significant co-morbidity: severe enough to require input from another specialty within secondary care, i.e. not simply with support from general practitioner or other primary-care professionals, for example with control of diabetes.

Exclusion criteria: where neither patient nor carer is fluent in English; although people with communication difficulties per se were not excluded.

Patients were initially identified and asked if they were willing to take part in the study by the relevant stroke specialist nurse and other members of the clinical team (see Box 2 for patient-inclusion criteria). In cases where, in the judgement of the consultant and/or clinical team, potential research subjects could not be approached by the researchers, they were asked to seek carers' approval for us to discuss the study with the carer, until such time as patients were able to indicate willingness to take part themselves. It was neither



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possible nor desirable to approach people who had had a stroke until several days – at least 7 days and sometimes more – afterwards. Patients and/or relatives were interviewed between two and eight (an average of five) times over the period of their journey from inpatient care, through rehabilitation to discharge into the community. This tracking of the care process for a period after return home (or entry into nursing or residential care) enabled us to assess process outcomes in terms of follow-up monitoring and review arrangements, in addition to the active care that we were able to study while patients were in hospital and/or rehabilitation.

In addition to undertaking in-depth interviews, members of the research team attended and observed strategic planning and operational-level service meetings in relation to both stroke and learning disability throughout the whole period of fieldwork. These included, for example, transitions co-ordinator network and Partnership Board sub-group meetings for learning disability. In the case of stroke, the researchers attended weekly multi-disciplinary team (MDT) meetings (where they took place) on the stroke wards (acute and rehabilitation) for a period of several months as the recruited patients progressed along the patient journey. They also attended relevant service planning groups such as the Standard Five/stroke sub-group of the NSF for Older People Local Implementation Team (LIT). Finally, the researchers examined patient/users case notes (where appropriate) in order to add detail to interview discussions (this was particularly important in the initial stages of tracking stroke patients when they were often too tired or unwell to talk in detail), and obtained local management reports and other documentation for subsequent analysis.

### ***2.5 The importance of in-depth interviews***

One of the main benefits of in-depth, face-to-face interviews as the main research method is that participants can give a detailed account of their experiences. Methods such as questionnaires are, by comparison, course-grained and two-dimensional. As well as their inherent richness, interviews take place at a particular time and are inevitably coloured by proximate experiences – however apparently mundane or even trivial in the context of overall care. This is one reason why we believed that it was important to interview patients/users and carers over a long period, covering time in hospital and following discharge with stroke patients, and with learning disabled young people as long a time as possible prior to and after leaving school. The longitudinal aspect of the study also allowed interviewees cumulatively to reflect on, and put into perspective, their whole experience.

It quickly became apparent, for example, when interviewing patients about those aspects of their treatment, rehabilitation and care that promote or impede continuity or seamlessness, that the apparently incidental can seem extremely important, at least in the period soon after it happened. As we shall see in Section 4, the allaying of concerns about relatives or small irritations about some ward routines can be seen as significant at the time. The same need for minimisation of worries and uncertainty was also true for service users and families interviewed in the context of learning disability transition (see Section 5). For both of our tracer conditions, our interviews were based on a topic guide (see Appendix 2) designed to reflect the major factors –

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structural and procedural, organisational and professional – which might influence continuity of care. This included a series of questions, with suitable prompts, not just about *what* the care or services received comprised but about *how* treatment, rehabilitation and care (for stroke patients) is given, and *how* the planning process is handled in terms of personal relationships between users/families and professionals (for learning disability).

We know from previous research (and indeed common sense) that how services are provided and care is given can be as important as what is given. Thus, for instance, it is little good stroke patients being given intensive therapy, or being given large volumes of information, or being closely involved in discharge planning, if it is done in a way that they think brusque, impersonal, thoughtless or hurried. Neither is it helpful if it is done in a environment perceived to be too noisy, or where the staff are too busy and pressurised to be as attentive to patients as they and families would ideally like. This is simply to make the point that environment, atmosphere and the personal approach of staff can be aspects of perceived continuity as important as how well co-ordinated is an agreed programme of treatment and care. Thus, in the language of the NHS Plan, the NSF for Older People and much other national guidance, continuity of care will be a product as much of a patient-centred approach and the general hospital environment as of adherence to any care pathway or model of care whether emanating from the Royal College's guidelines, the NSF or elsewhere (although clearly that is still needed). Similarly, for young people with a learning disability and their families it is as much about the way in which they are included in the transition planning process (i.e. as full partners, or simply on the receiving end of decisions that feel like they have already been made) as the types of services they eventually receive.

### ***2.6 Remainder of the report***

Section 3 contains a detailed account of the policy context in which the two services are provided. Sections 4 and 5 are the heart of the report and set out to do two things. First, they outline in detail the geographical location, and organisational and professional boundary arrangements in our case-study localities. Second, they describe continuity (and discontinuity) as experienced across the stroke patient journey from inpatient care, through rehabilitation, to discharge into the community; and the transition from childhood to adulthood for young people with a learning disability. In doing so, Sections 4 and 5 highlight, both from NHS and social services manager and staff viewpoints, and from the perspective of patients/users and carers, the features that promote or impede continuity for those receiving learning disability and stroke services.

It is important to emphasise that, for each tracer condition, the remainder of the report explicitly looks at issues of a general nature across the sites. It is not intended to be a detailed description of activity in any one locality. Instead, the aim is to identify recurring features that constitute continuity of care. In this way we hope to locate our own fieldwork within a wider context that will allow lessons of a more general nature to be drawn. Our general observations are pulled together in the final section of the report (Section 6).

## Section 3 National policy context

### **3.1 Joined-up government, policy-making and service delivery: general**

One of the hallmarks of the Labour Government, since first elected in 1997, has been the drive to ensure joined-up service planning and delivery. The phrase joined-up government itself represents an acknowledgement that, hitherto, public service provision has all too often lacked co-ordination and integration. It also reflects a growing realisation that the most complex social problems cannot be tackled by the traditional 'silo' mentality associated with separate Whitehall departments working with equally separate policy communities. Indeed, it is a recognition that by perpetuating fragmented policy-making and implementation such separatism – at both national and local levels – merely compounds the so-called cross-cutting problems.

What is striking about the commitment to joined-up government is not its novelty – it has a long and largely melancholy history (see Challis *et al.*, 1988) – but its endurance and the extent to which it has penetrated policy-making and implementation across the public services. In different guises the drive for co-ordination has also spanned every level of policy-making from the commitment to joined-up government across Whitehall by the Prime Minister, Cabinet Office and Treasury, to the statutory duty of partnership (upon health and local authorities) introduced by the Department of Health, to the call for whole-system working in pursuit of seamless services for individual service users.

This emphasis on co-ordination and joint working – not fragmentation and organisational/professional separatism – has outlived the modernisation banner under which it was first launched. Expressed in terms of the need for an alternative (network) mode of governance, joined-up government is also an important manifestation of the Third Way heralded by the newly elected Government in 1997.

The Government, in its second term especially, has underlined the importance of final service delivery – the public services as experienced by their recipients. This study has provided an opportunity to test the extent to which the rhetoric of joined-up government, whole-system working and service integration has been given operational expression in services which are perceived as joined-up/seamless/continuous by their recipients.

At the forefront of the modernisation programme was the White Paper on the modernisation of government itself, published in March 1999. In his introduction to the White Paper the then Cabinet Office Minister Jack Cunningham spelt out clearly the need for better co-ordination:

*...we need all parts of government to work together better. We need joined-up government. We need integrated government.*

(Cabinet Office, 1999)

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Describing modernisation as central to the government's purpose, the White Paper referred to the keystones of its strategy as inclusiveness and integration. Integrated policies and programmes, it was argued, 'tackle the issues facing society...in a joined-up way, regardless of the organisational structure of government' (ibid, para 1.7). This requires 'working across institutional boundaries' (ibid, para 1.12). Arguing that there had been some areas where effective co-ordination and collaboration are the norm (such as foreign and security policy) it was accepted that in general there was too little joined-up working, either horizontally across government departments or vertically between the centre and the periphery. If the general history, and problem, is of fragmentation across institutional boundaries, the challenge 'is to get different parts of government to work together' (ibid, para 2.6) by, among other things, 'designing policy around shared goals and carefully designed results not around organisational structures or existing functions' (ibid).

The White Paper made repeated references to cross-cutting issues and cross-cutting policies. Cross-cutting issues – among the most obvious being poverty, crime and social exclusion – are those not amenable to being dealt with by any single minister or department but only collectively. The White Paper listed a series of organisational and policy initiatives to foster joined-up working. Among the most important was the strengthening of co-ordination at the heart of government via the creation, within an expanded Cabinet Office, of the Performance and Innovation Unit (see below). Other initiatives cited were management of the criminal justice system as a whole (by the Home Office, Lord Chancellor's Department and Crown Prosecution Service), and a wide range of citizen-focused, group-focused and area-based programmes: for example, NHS Direct, Better Government for Older People and Health Action Zones, respectively.

There was frank acknowledgement of the problems for front-line agencies caused by different audit, inspection and performance-management arrangements – a good example being the separate mechanisms for health care and for social care. There was an equally frank acknowledgement of the problems caused by a multiplicity of administrative boundaries. These, it was said, 'can lead to inefficiency, complication and confusion' (ibid, para 2.3). The intention to address these problems was made clear. In the case of separate performance management and inspection the Government proposed to

*...encourage a whole systems approach. We will put the focus on assessing improvements in the effectiveness and value for money of a whole system...not just in its constituent parts.*

(ibid, para 4.6)

In future, it was stressed, audit would no longer be an excuse for failing to deliver more co-ordinated services. As regards non-conterminosity the Government was clear in its stated intention to align organisational boundaries:

*More than 100 different sets of regional boundaries are used in England alone. This complicates administration, reduces efficiency and frustrates joined-up government. It also confuses the public. Wherever possible boundaries should coincide with local authority boundaries at local level.*

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(ibid, para 3.23)

In order to identify and highlight some of the confusion and practical problems facing people using public services, several Integrated Service Teams were set up in 1999. They looked at seven of the most common 'life episodes', one of which was the need for long-term care at home. Illustrating the difficulty for people negotiating their way through a plethora of organisations, the White Paper effectively demonstrated the potential discontinuities within and across bewilderingly complex systems.

It was in this same context that the creation of the Performance and Innovation Unit (PIU) was announced in July 1998, following a review of the effectiveness of the centre of government by the Cabinet Secretary, Sir Richard Wilson. The unit's aim was 'to improve the capacity of government to address strategic, cross-cutting issues [and be] part of the drive for better, more joined-up government' (Cabinet Office, 2000a, Annex A1). The PIU produced the following three reports, addressing the theme of joined-up government, which, in their examination of partnership, complexity and integration, provide part of the broad policy context for this study.

- *Wiring it Up*: Whitehall's Management of Cross-cutting Policies and Services (January 2000; Cabinet Office, 2000a)
- *Reaching Out*: the Role of Central Government at Local Level (February 2000; Cabinet Office, 2000b)
- *Strengthening Leadership in the Public Sector* (March 2001; Cabinet Office, 2001).

### 3.1.1 Wiring it Up

Commissioned in 1998, the PIU's brief from the Prime Minister for *Wiring it Up* was simple: 'to remove some of the barriers that sometimes stand in the way of "joining-up"' (Cabinet Office, 2000a). Although the specific focus of the unit's study was central government the analysis is of wider relevance. The unit's report was straightforward in its description of longstanding problems. Whitehall structures:

*can inhibit the tackling of problems and issues which cross departmental boundaries (so-called 'cross-cutting issues') because, amongst other things 'budgets and organisational structures are arranged around functional lines [e.g. health] rather than horizontal, cross-cutting problems' [e.g. social exclusion].*

(ibid, p.6)

The report echoes our own findings on the principal barriers to joint working (Hardy *et al.*, 1989, 1992, 2003; Hudson *et al.*, 1999). Such barriers are not only, or mainly, structural – of the sort referred to in the above quote – but also professional, attitudinal and cultural. The report's authors thus refer to 'the signals which Ministers give civil servants about the priority they wish to be given to cross-cutting approaches [being] key to it all' (Cabinet Office, 2000a, p.5). They refer also to the need for 'a fundamental change of mind-set...switching from a culture of tribal competitiveness to one of partnership' (ibid, para 8.9).

The report stressed repeatedly the complexity of cross-cutting working and recommended that civil servants be given practical experience of 'handling

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the conflicts of interest and complex reporting lines of genuine partnership working' (ibid, p.7). Cross-cutting working is described as 'difficult to manage' and 'inherently more risky because it involves complex relationships and lines of accountability' (ibid, p.8). Moreover, if the ways in which work is appraised and rewarded – the incentive structures – 'are incapable of identifying and rewarding a contribution to a successful cross-cutting project, the risks are one-way' (ibid, para 3.2). In other words, vertical lines of management within Whitehall departments foster a narrow departmental view, which leads not just to a narrow, constricted view of issues and problems but a failure to identify – or propensity to distort – problems that span departmental boundaries. Such departmental separatism is then made worse by weak or even perverse incentives for cross-cutting working, a perversity reinforced by separate performance-assessment mechanisms (audit, inspection and review).

The report cites social exclusion as an example of 'a joined-up problem [that] has never been addressed in a joined-up way': one which 'for many years was tackled less effectively as a series of isolated departmental issues' (ibid, para 7.1). Such problems, it is candidly recognised, have 'fallen through the cracks between Whitehall departments or between central and local government' (ibid, p.8). There is an equally candid recognition of the effects of fragmentation; effects graphically illustrated by the example of housing and community care:

*Those on the receiving end of centrally-made policy – whether deliverers or services recipients – are often left to try to make sense of the unco-ordinated messages, policies and funding streams passed down by Whitehall departments.*

(ibid, para 7.1)

And although action was said to be in hand 'to rationalise some of these lines' it was accepted that 'they will inevitably remain complex and the health and well-being of some very vulnerable people will continue to depend upon effective inter-departmental and inter-agency co-ordination' (ibid, para 7.2).

### **3.1.2 Reaching Out: the Role of Central Government at Local Level**

Published in February 2000, the PIU's report *Reaching Out* (Cabinet Office, 2000b) dealt with some of the problems of 'vertical' fragmentation – or insufficient co-ordination between centre and periphery. In his foreword to the report, the Prime Minister accepts bluntly that

*In the past government structures have too often been over-centralised [and] insufficiently joined-up... Improving the co-ordination of services is a top priority.*

(Cabinet Office, 2000b)

The report speaks of problems 'becoming more acute, and greater importance is attached to integrated solutions to local problems'. Such problems, it was argued, were made worse in part by the Government's establishment of a large number of separate area-based initiatives or zones targeting particular local areas. What was apparent was 'the need for central government to relate to local government in a holistic way' (ibid, Executive Summary, para 7). There was a strikingly blunt recognition of a criticism frequently voiced at

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local level – that of ‘initiativitis’. There was said to be ‘clear evidence...that there are too many government initiatives causing confusion; not enough co-ordination and too much time spent on negotiating the system rather than delivery’.

### **3.1.3 Strengthening Leadership in the Public Sector**

In its 2001 report on public-sector leadership (Cabinet Office, 2001) the PIU explored the nature and degree of complexity in public-sector service delivery. ‘Organisational life’, was described as ‘systemic without being systematic’: and ‘joined-upness is not merely a political goal; it is an inescapable element of organisational life’ (ibid, Annex D, paras 16 and 17).

The report notes ‘an increased pressure for seamless, personalised services, so that even where many agencies are involved, services meet the needs of the user, rather than the organisational convenience of the producers’ (ibid, 2.9). The report also refers to ‘the challenge of a more complex political and institutional architecture’ (ibid). Describing the nature of the challenge facing the public sector as that of delivering ‘joined-up services through networks and loose coalitions’ (ibid, para 3.7), collaboration is said to be ‘a critical dimension...because the final objective is not the interest of the individual organisation but...overall outcomes’ (ibid, para 3.6). And although there was acknowledged pressure to deliver ‘vertical’ services more effectively there was, it was argued, ‘a greater demand for ‘horizontal leadership within and across sectors’. Leaders in the public sector, where – notwithstanding the imperatives associated with internal markets and mixed economies of care – the prevailing ethos was still of collaboration not competition, ‘need to collaborate more, manage change through others and focus on customers whose problems may not be susceptible to solution by a single agency’ (ibid, para 2.10). The report describes good leaders as those who ‘find effective ways of participating in partnerships and build coalitions, joint ventures and inter-organisational networks’ (ibid, para 3.9).

### **3.1.4 Commitment, changing cultures and changing modes of governance**

There are several points to make about this succession of publications seeking more joined-up government in pursuit of better co-ordination of service policy-making and delivery. First, that they emanate from the centre of government and have the Prime Minister’s personal stamp of authority. Second, that there is a clear recognition that working across organisational and professional boundaries is complex as well as difficult – and much more complex than working within traditional organisational hierarchies. Third, that there needs to be a fundamental shift away from working purely within these ‘command and control’ structures to working ‘in complex cross-cutting teams’ (ibid, para 8.10): that is, a shift from hierarchy to network forms of working. Fourth, that the barriers to joined-up working are not simply structural but attitudinal and cultural. The reports themselves are one important means of changing organisational and professional cultures. Coming as they do from the Cabinet Office the reports were also intended to give the message that joined-up working was neither optional nor peripheral.

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Interestingly, there were joint lead ministers responsible for the implementation of *Wiring it Up*: the Minister of State in the Cabinet Office and the Chief Secretary to the Treasury. There was also no doubt that the view from 'the centre' which these PIU reports expressed comprised the triumvirate of 10 Downing Street, the Cabinet Office and the Treasury (Cabinet Office, 2000a, p.15). The Treasury's role was crucial not just symbolically but in leading a series of cross-cutting reviews as part of the Spending Review in 2000 (and, thereafter, in 2002 and 2004). Moreover, of 160 Public Service Agreement targets set in the 2000 Spending Review, responsibility for 30 was shared by more than one Whitehall department.

What is also interesting is that the Joined-up Public Services website operated by the Cabinet Office in 2001 is now retained purely for archive purposes; the archive noting that the modernising government programme has been completed. The PIU was absorbed within a newly formed strategy unit (within the Cabinet Office) in June 2002. But a year before, in June 2001, the establishment of the Prime Minister's Delivery Unit marked the shift in focus from identifying problems and designing solutions to securing tangible changes in front-line service delivery. As the Cabinet Office website made clear, joined-up working was not an end in itself, but for a purpose: 'high quality, modern and responsive services'.

The Government commitment was to secure such services, in pursuit of which its twin purpose was to set out the need for joined-up working and then to encourage and facilitate it. The need itself was summarised on the Cabinet Office website.

*Joining-up means making sure that citizens and businesses come first. It means a genuine partnership between those providing services and those using them. We know from our research that people have grown impatient of barriers to effective and convenient services that stem simply from the way government is organised. People should not have to worry about what part of government they are dealing with. The public sector must deliver services and programmes that are not only efficient and effective but also joined up and responsive.*

(Cabinet Office, 2001)

The importance of this message coming from the centre of government has been in setting not just the tone but the broad accountability framework within which joined-up working in all its guises – partnership working, whole-system working – has been pursued in and across a range of policy areas. This then was the broad policy context within which the sites in this study were operating at the beginning of the study: although, as discussed below, health and social care is a policy area in which the combination of political sensitivity and a disappointing history has led to more than mere acknowledgement or exhortation from the centre. Here joined-up working was made a requirement – a statutory duty. Joint planning in the field of health and social care has in fact been a formal requirement for 30 years but this has not only generally been against the grain of practice in the public sector but across a series of deep fault lines. In this specific context the strengthened imperative to joined-up working in health and social care since 1997 – expressed as a specific statutory duty – has been made even stronger in this wider context of joined-up government being a consistent prime ministerial priority for the public sector.



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### **3.2 Joined-up government policy-making and service delivery: health and social care**

One of the Labour Government's first applications of Third-Way principles to its modernisation agenda was in the proposed reform of the health service. Thus, in the 1997 White Paper *The New NHS: Modern, Dependable* (Department of Health, 1997) 'partnership' was advanced as an explicit rejection of prior modes of governance – the 'old centralised command and control systems of the 1970's and the "divisive internal market system of the 1990s"' (ibid, para 2.1). In his foreword to the White Paper the Prime Minister described it as 'a turning point for the NHS. It replaces the internal market with integrated care' (ibid). Although it has been a pervasive feature of the two Labour Governments since 1997, partnership has been accorded particular prominence in the field of health and social care (Clarke and Glendinning, 2002). This, as indicated above, is partly because it represents a third way between these two 'failed' forms of governance and partly because it is an attempt to bridge or overcome deep fault lines which have existed since the establishment of the NHS in 1948.

The Government's NHS Plan (Department of Health, 2000) sought to rectify these longstanding fault lines – not only the so-called Berlin Wall between health and social care but the divide between public-sector (NHS) and non-public-sector (voluntary- and, especially, private-sector) healthcare. We have written at length about this history of problematic joint working, particularly in respect of the first of these two fault-lines (see, for example, Hardy *et al.*, 1989, 1992; Hudson *et al.*, 1999, 2002; Glendinning *et al.*, 2002; Hudson and Henwood, 2002). The 1997 White Paper was followed a year later by publication of a discussion document, *Partnership in Action* (Department of Health, 1998), which rehearsed the longstanding barriers to joint working between health and social services. This led in turn to the 1999 Health Act, Section 31 of which introduced new 'partnership flexibilities' designed to overcome the principal barriers to joined-up working. Use of these flexibilities – pooled budgets, lead commissioning and integrated service provision – was optional. The Department clearly expected extensive early use of the flexibilities. In practice their initial use, from April 2000, was extremely limited (see Glendinning *et al.*, 2002). It was in part this disappointing take-up that prompted the Government in The NHS Plan to announce proposals for structural change. This would take the form of new integrated health and social care commissioning organisations – Care Trusts.

In April 2002 the Department of Health published *Delivering the NHS Plan* which referred to the 'new national architecture' put in place in the government's first term in office being 'right' (Department of Health, 2002a, Executive Summary, para 8). There was a blunt assertion that 'the NHS Plan is working' and a restatement of the Government's commitment to its implementation 'as the cornerstone of our NHS reforms' (ibid, para 1.5). There was a confident assertion that the 'reforms are beginning to bite' in particular with services 'being redesigned as barriers between health and social care start to be broken down' (ibid, para 1.4). However – as continuing limited use of the Section 31 flexibilities showed – there were still some 'outdated organisational and professional barriers' (ibid, para 1.3). As in the 1997 White Paper and the 2000 NHS Plan there was a frank acknowledgement

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of 'some profound and historic weaknesses in the NHS', – including 'health and social care systems that work against each other when older people particularly need them to work together' (ibid, para 1.8). There was said to be an understanding of the structural weaknesses and a recognition that more needed doing to help the caring professions in 'breaking down the barriers between health and social care' (ibid, para 1.10).

Thus, 5 years after the NHS White Paper in 1997 there was yet further explication of 'the case for a radically different relationship between health and social services, particularly to improve care for older people' (ibid, Executive Summary, para 14). The document speaks of moving towards 'one care system'. It is worth quoting at length the relevant passages in this April 2002 document because, in a context in which the broad architectural changes were judged appropriate, they clearly distil the Government's concern (at the start of our study) with continued service fragmentation – especially between health and social care – and its expectation (and requirement) that care be designed and delivered around the needs of individual patients and service users.

*Patients, particularly older people, need health and social services to work together. They rely on good integration between the two to deliver the care they need when they need it.*

(ibid, para 8)

The extra resources which the Government had committed to the NHS provided, among other things:

*The opportunity for further steps on reform towards the NHS Plan vision of a single care system which is organised in the interests of its users not providers. Although progress has been made towards breaching the 'Berlin Wall' between health and social care there are still too many parts of the country where a failure to co-operate means that older people fail to get the holistic services they need.*

(ibid, para 8.4)

The document makes special reference to older people:

*The commitment to deliver patient-centred care – the right care in the right place at the right time – must above all, be honoured in the delivery of care for older people. And older people above all others have a right to expect that their care is delivered seamlessly through a range of services that are convenient and as close to home as possible.*

(ibid, para 8.5)

This document, in line with other such documents, makes no explicit reference to 'continuity of care'. But here – once again as elsewhere – we can take references to the Government's commitment to seamless care and to patient-centred care as being synonymous with a commitment to 'continuity of care'.

As indicated above, part of the context within which *Delivering the NHS Plan* was written was some frustration at the slow pace and limited use of the Section 31 flexibilities. Against the background of further consideration being given to structural reform – in particular the creation of Care Trusts capable of designing unified health and social care – the document referred to the Government's intention 'to introduce new arrangements to ensure a more seamless services [*sic*] for patients' (ibid, para 8.9). Although PCTs were

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helping bridge the gap between hospital and community services 'more needs to be done to bridge the even wider gap between health and social care provision' (ibid, para 8.8).

There was an acknowledgement that not all of the problems lay at local level. There was, it was accepted, 'fragmentation in the structure of NHS inspection' (ibid, para 10.6) and 'fragmentation and confusion' (ibid, para 10.10) in the inspection of social services. However, the proposed changes – for a new Commission for Health Audit and Inspection and a new Commission for Social Care standards – perpetuated the operation of two separate inspection systems. Even in their new guises – as the Healthcare Commission and Commission for Social Care Inspection – this remains a source of fragmentation, irrespective of any requirement upon the inspection agencies to co-operate. This seems at odds with two concluding statements in the document. First, that 'older people and other service users have the right to expect that local services are working as one care system not two' (ibid, para 8.12). Second, that the reforms being introduced 'will bring health and social care closer together than at any time since the birth of the NHS' (ibid, para 11.8).

It is clear that these reforms need to encompass a wide range of elements: the duty of partnership, the creation of Care Trusts and the further development of a range of standards and targets – albeit the latter being far fewer in number. It seems equally clear that inter-organisational complexity will remain a barrier to joined-up working so long as service integration is required across a large number of non-conterminous organisational boundaries.

This latter point was made strongly in an influential report by Derek Wanless in February 2004. In 2002 he had produced his first report, *Securing our Future Health* (Wanless, 2002), setting out the long-term investment required to sustain and build the NHS. Commissioned again by the Prime Minister, Secretary of State for Health and Chancellor of the Exchequer, the second Wanless report, *Securing Good Health for the Whole Population* (Wanless, 2004) focused on public health. It cast a critical eye over historical developments and the succession of previous official reports which appeared to have had little impact upon service delivery. The report spelt out clearly some of the problems associated with inter-organisational complexity and the organisational turbulence surrounding major service re-organisation. Difficulties in delivery were due partly to 'the complexities of the delivery chain, the gaps in and duplication of functions' (ibid, p.39) partly to capacity problems, but also to 'the impact of recent organisational changes and the lack of alignment of performance management mechanisms between partners' (ibid, p.8). Indeed, this, it was argued, was not just a recent problem: 'repeated restructuring has tended to weaken the NHS over decades' (ibid). Noting that 'shifting the balance of power' represented a major structural change to the NHS, Wanless argued that 'in some areas the disruptive impact of re-organisation is still being felt' (ibid, para 3.20). 'Particular problems', he argued, 'relate to the size of PCTs and capacity and the dispersal of the workforce' (ibid, para 3.21).

Wanless was correspondingly clear about the benefits of reduced complexity – via conterminosity – and of increased integration of health and social care. 'There is', he says, 'an important role for social care in minimising demand for

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health care' (ibid, p.10). And increasingly productivity in healthcare is 'likely to involve integration of thinking about health and social care' (ibid, para 1.24). Such integration will in large part depend upon well-developed partnerships between health and social care commissioners and providers. Noting the plethora of partnerships that have developed at a local level in recent years (ibid, para 3.79), Wanless argues that 'Partnership working seems essential to improve the health of the population' (ibid, para 3.87).

*'And whilst in some areas there are signs of strong partnership working between PCTs and local government' (ibid) there was in many areas 'a particular problem [of] lack of conterminosity between local authority and PCT boundaries and the relationships between PCTs and two-tier authorities. When the geographical boundaries (and hence population saved) are not aligned, it is more difficult to co-ordinate activity and increases the number of partnerships with which PCTs and local authorities must engage'.*

(ibid, para 3.85)

And 'amen to that' would be the response from service managers and professionals alike across the case-study localities in this study. They also strongly argued the converse: that the relative inter-organisational simplicity of conterminous PCT and local-authority boundaries – and, just as importantly, NHS Acute Trust boundaries – is an immeasurable aid to partnership working and to the planning and delivery of integrated local services. There would also be broad agreement that conterminosity does not guarantee good partnership working and effective integration but it provides a solid foundation. By contrast non-conterminosity is an inherently weak foundation: not one that it is impossible to build upon, but one that invariably is much more difficult. The 2004 Wanless report underlined not just the difficulties but the complexity involved in planning and delivering services across a range of organisations. 'The important issue', he said, 'is the recognition that 'developing partnerships and joint planning or service delivery with a range of organisations can be complex and requires sufficient expertise and capacity' (ibid, para 3.89). He also called for a recognition – in terms of external performance management and inspection – of 'the complexity of partnership working in areas where the number of partner organisations is large due to the lack of conterminosity'. (ibid, 3.88). As we shall see, such difficulties and complexities were widely thought to be significantly increased by the organisational turbulence (and associated discontinuities of staffing and placing) surrounding the re-organisation of primary care in 2002.

Shortly after publication of the second Wanless report the Government published *The NHS Improvement Plan* (Department of Health, 2004a) and the second joint health and social care planning framework (Department of Health, 2004b; for the years 2005/2006–2007/2008). In *The NHS Improvement Plan* the Government set out what it described as the next 4-year stage in the NHS's journey. This is intended to build upon the previous 4 years' 'track record of success', established by the investment and reform initiated by the NHS Plan in 2000 (and by the first Wanless report in 2002). The next stage 'is to ensure that a drive for responsive, convenient and personalised services takes root across the whole of the NHS' (Department of Health, 2004a, para 4). The claim is that already 'a new spirit of innovation has emerged, centred on improving the personal experience of patients as individuals' (ibid, para 24). In the planning framework document (Department

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of Health, 2004b) the NHS Chief Executive lists five points which, he says, underpin this next phase of reform. The first point is 'a focus on health and wellbeing across the whole system' which 'requires health organisations and Local Authorities to work even more closely together to pay attention to the whole range of health and social care services' (ibid, p.5). The Department says it looks to PCTs and local authorities to build on Local Strategic Partnerships (LSPs) and 'lead community partnership by even closer joint working' (ibid, p.7). The framework sets out six principles for local target setting, one of which is that they 'are developed [by PCTs] in local partnership with other NHS bodies and local authorities' (ibid, para 15 p.11). Indeed PCTs are also expected to work in partnership with 'service providers, patients and service users' to ensure that their plans 'are based around the whole care pathway and not limited by individual organisational boundaries' (ibid, para 16, p.12). The planning framework document also speaks of 'the local health and social care economy' (ibid) and 'the new NHS and social care system' (ibid, para 19, p.14). Notwithstanding this reference to a single system the new standards set out in the planning framework document 'are confined to the provision of NHS health care' (ibid, Annex A, para 31); although authorities are reminded of the statutory duty of partnership established under the 1999 Health Act and the 2003 Health and Social Care (Community Health and Standards) Act. And, once again, in spite of this apparently limited focus, 'there is', it is said, 'a considerable emphasis within the development standards to adopting a whole system approach to health service provision' (ibid, para 32).

The planning framework document makes it clear that the 'core' standards which it sets out 'are not optional'; and, indeed, these should be met from July 2004, the date of their publication. The 'development' standards are intended to be 'a dynamic force for continuous improvement' (ibid, para 19) and are something 'against which health organisations will be judged in annual reviews by the Healthcare Commission' (ibid). The phrase continuity of care is not used in the standards. There are, however, several references to its most common synonym, seamless care.

Of the seven domains, five are in some way germane to this study. The second domain – Clinical and Cost Effectiveness – has as a core standard the need for healthcare organisations to 'co-operate with each other and social care organisations to ensure the patients individual needs are properly managed and met' (core standard C6). This is closely echoed by one of the core standards (C22) in the seventh domain – Public Health – which requires healthcare organisations to promote and improve community health by, among other things, 'co-operating with each other and with Local Authorities and other organisations' and by 'making an appropriate and effective contribution to local partnership arrangements, including Local Strategic Partnerships' (ibid, p.34). What is interesting from the perspective of this study is that the related developmental standard (D2) refers to patients receiving effective treatment and care that, among other things, 'are well co-ordinated to provide a seamless service across all organisations that need to be involved, especially social care organisations' (ibid, p.29)

There are close links here to the fifth domain – Accessible and Responsive Care – the intended outcome of which is that 'patients receive services as promptly as possible...and do not experience any unnecessary delay at any

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stage of service delivery or of the care pathway' (ibid, p.33). The fourth domain – Patient Focus – has an intended outcome specifying 'partnership with patients, their carers and relatives...and other organisations (especially social care organisations) whose services impact on patient well-being' (ibid, p.31). Core Standard C16 under this domain refers to healthcare organisations providing patients with suitable information on care, treatment and after care. A related development standard (D9) refers similarly to patients, service users and, where appropriate, carers receiving timely and suitable information (ibid, p.32).

These latest national standards post-date the fieldwork for this study, but they echo many of the existing standards in Scotland and reflect many of the standards laid down in NSFs in England – and other exhortations to joined-up working – intended to guide local service delivery at the point where, as the Government has repeatedly stressed, it matters most: that is, the individual service recipient. The question for this study is to assess the extent to which within this broad context of general (pan-Government, pan-public-sector) exhortations, specific legal requirements and detailed guidance to work in partnership, the experience of service recipients is of integrated services that are joined-up not only over time – sequential continuity – but at any one point in time – simultaneous continuity.

In terms of what was wanted (and expected and required) by way of joined-up/whole-system working, the policy context could hardly have been more forcibly expressed. The questions to local service commissioners and providers and to service managers and service professionals which we were addressing were: (a) whether the apparent structures and policy instruments were in place; (b) whether enough of the institutional complexity – in terms of non-conterminous boundaries, different funding streams and different performance management frameworks – had been lessened if not removed and (c) whether there was the right culture and sufficient commitment to overcome the longstanding tendencies to organisational and professional separatism.

## Section 4 Stroke case study

### **4.1 The policy context**

The main policy document for stroke services in England is the NSF for Older People, published in 2001 (Department of Health, 2001b). The NSF is presented in eight discrete Standards, with Standard Five covering stroke services. In common with other NSFs, Standard Five focuses principally on the available experimental evidence about stroke services, including evidence about the circumstances when computed tomography (CT) scans are justified and when therapeutic inputs are likely to be cost-effective.

Standard Five also presents three types of evidence about the organisation of services. The first is evidence that there should be, 'specialist stroke teams led by a clinician with expertise in stroke' (ibid, para 5.31) where, 'stroke teams will be involved in all aspects of stroke services' (ibid, para 5.32). Thus there is a clear expectation that hospitals should have dedicated stroke teams. The second type of evidence – although the standard indicates that the experimental evidence base is weak here – is that a range of clinicians and other service providers, such as social services staff, should be part of the wider stroke care team. The third type of evidence is that stroke services should have stroke co-ordinators. The nature of the stroke co-ordinator role is not defined in any detail, but it is made clear that the role could be undertaken by doctor, nurse or other clinician. The NSF states that the co-ordinator will be responsible for (ibid, para 5.25):

- co-ordinating assessment and individual care plans and ensuring arrangements for support and secondary prevention measures are in place prior to discharge;
- ensuring an efficient flow of relevant information to community-based professionals;
- ensuring a smooth transfer between care settings;
- ensuring that the need for home adaptations, repairs and improvements are identified, and work completed pre-discharge.

In similar vein the NSF goes on to say that:

*Treatment should be initiated in hospital, with arrangements made with the primary care team for it to be continued after discharge. Patients and their families should be provided with information, advice and support to prevent further strokes, and GPs notified of the risk factors and steps that have been, or will be taken, to reduce risk.*

(ibid, para 5.26)

The NSF makes further detailed comments, including that stroke teams should meet at least weekly to discuss patients' progress and that appropriate links should be made with other public-sector bodies (e.g. housing departments) and voluntary organisations (e.g. the Stroke Association, Different Strokes or minority ethnic community organisations).

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The NSF also contained milestone targets for the implementation of improved stroke services across England. The main milestone concerned the creation of specialised services. This was reiterated in the subsequent Priorities and Planning Framework for 2003–2006 (Department of Health, 2002b):

*By April 2004 all general hospitals caring for people with stroke to have a specialised stroke service, and all health and social care systems to have established an integrated falls service by 2005.*

Standard Five focuses mainly on clinical services, but two other standards – Two and Three – emphasise the importance of developing person-centred services for older people. Standard Two covers person-centred care, and contains guidance on assessment of individuals' needs, set mainly in the context of the implementation of the Single Assessment Process (SAP).

Standard Two is:

*NHS and social care services treat older people as individuals and enable them to make choices about their own care. This is achieved through the single assessment process, integrated commissioning arrangements and integrated provision of services, including community equipment and continence services.*

The standard goes on to state that:

*Staff working in services for older people and their carers will be supported in their aim to deliver person-centred care across organisational boundaries by joined-up processes for commissioning and delivering older people's services.*

(Department of Health, 2001b, paragraph 2.18)

Standard Three sets out plans to implement intermediate-care services. While intermediate care overlaps only partially with stroke care in practice, this standard contains further statements about the importance of continuity of care, and it seems reasonable to assume that the same principles apply to both types of service. Thus, for example, Standard Three states that:

*An essential component of intermediate care services is that they should be integrated within a whole system of care including primary and secondary health care, health and social care, the statutory and independent sectors. This creates challenges for the commissioning, management and provision of care entailing complex multi-sectoral work. Intermediate care cannot be the responsibility of only one professional group or agency.*

(ibid, paragraph 3.11)

Standard Four of the NSF sets out evidence about the quality of general hospital care that older people should receive. It makes similar points to Two and Three:

*Better care should be provided throughout the older person's stay in hospital, from early emergency care, and including very specialist care through to discharge. The challenge is to ensure that hospitals are organised so that specialist care is readily accessible, and that all staff have the support they need to care for older people.*

(ibid, paragraph 4.3)

In all four standards, then, there is a clear implication that there should be appropriate and timely care, provided on the basis of the assessed needs and thus tailored to the needs of individuals. It is difficult to find explicit statements about continuity of care, but equally difficult to come away from the NSF without appreciating that it is a central concern of policy-makers.



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### **4.1.1 Scottish Intercollegiate Guidelines Network**

The Scottish Intercollegiate Guidelines Network (SIGN) has published guidance on the diagnosis and treatment of a wide range of clinical conditions. There have been four separate publications on stroke care. The most relevant report for this study was originally published in 2002 (Scottish Intercollegiate Guidelines Network, 2002), and updated in January 2005, and covers rehabilitation, discharge planning and the management of complications. In many respects the SIGN guidelines are similar to NSFs in England. They seek to present the best available evidence about the clinical aspects of stroke care in an easily accessible way. In important ways, however, the thinking behind the SIGN guidelines differs fundamentally from the thinking behind NSFs.

Two aspects of the SIGN stroke guidance concern us here. First, the guidance is organised around the main steps in the care pathways taken by most people who have strokes. As a result, the guidance contains more information than the English NSF on the decision-making, assessment and routing of people with strokes. The process of care is more prominent than in the English guidance. Second, the SIGN guidance is more explicit about the roles of clinical staff needed in a stroke team, notably the therapists who each have a section describing their roles. This said, the SIGN guidance takes the view that continuous care is desirable, but does not present any stronger evidence than that found in the NSF for Older People: if anything, the Scottish guidance lacks the patient and carer perspective provided by Standards Two and Eight in the English NSF.

### **4.1.2 The role of guidance – and of this report**

NSF- and SIGN-style guidance, by its nature, contains limited evidence of the kind that is presented in this research report. The main purpose of official guidance is to present the best available experimental evidence, and is part of a general international trend towards quality improvement, as evidenced by the European Stroke Initiative (see [www.eusi-stroke.org/l3\\_pdf/EUSI2003\\_Cerebrovasc\\_Dis.pdf](http://www.eusi-stroke.org/l3_pdf/EUSI2003_Cerebrovasc_Dis.pdf)). This type of guidance does not seek to guide NHS staff on issues of service delivery and organisation. This section can, therefore, be viewed as providing complementary evidence that service providers and managers need to organise and deliver services. They need guidance on both the organisation of services and best practices in treatment, diagnosis and care.

The need for this type of research is highlighted by the difficulty of pinning down the meaning of key terms. The main milestone in NSF Standard Five, updated in the Priorities and Planning Framework (Department of Health, 2001b, 2002b), uses the term 'specialized stroke service'. But what is a specialised stroke service? We were not able to find a concise definition of the term in policy guidance, or a clear account of the relationship between the terms 'specialised stroke service' and 'stroke unit'.

However, there is a carefully worded definition of a stroke unit in the Royal College of Physicians' (2004) Sentinel Audit.

**Stroke unit** – *a multidisciplinary team including specialist nursing staff based in a discrete ward which has been designated for stroke patients. This category includes the following subdivisions:*

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(a) **Acute stroke units** which accept patients acutely but discharge early (usually within 7 days). This could include an 'intensive' model of care with continuous monitoring and high nurse staffing levels.

(b) **Rehabilitation stroke units** which accept patients after a delay of usually 7 days or more and focus on rehabilitation.

(c) **Combined** (i.e. no separation between acute and rehabilitation beds) stroke units that accept patients acutely but also provide rehabilitation for at least several weeks if necessary.

Implicitly, a specialised stroke service is a stroke service provided by a multi-disciplinary team – but membership of the specialised service, the location of the boundaries between specialised and mainstream health services (e.g. general practice) and whether it covers only hospital care or extends into primary and community care, are not clear. In short, the nature and purpose of specialised stroke services is not defined in policy documents. This should not be taken as a direct criticism of current policies: it does, though, help to make the point that the NSF and other high-level documents do not focus on this sort of issue.

Another important role for this sort of guidance is to signal that a service should have priority status within public service organisations. Standard Five of the English NSF contains important statements about the quality of care that should be provided to anyone who has a stroke in England. It is also striking, though, that stroke care is not given the same status as other conditions. Cancer and coronary heart disease, for example, had their own NSF or equivalent (the Calman–Hine report in the case of cancer). In both cases the publication of evidence-based guidance was accompanied by announcements of substantial increases in funding for those services. Stroke, in contrast, did not receive any additional monies after 2001. The apparently anomalous position of stroke in England is heightened by comparison with the situation in Scotland, where stroke has been identified as a priority for service development and thus has broad parity with coronary heart disease and other major services. As this section shows, additional funding and its associated raised profile would make a positive difference to peoples' experiences of stroke care in England.

### **4.1.3 Other guidance**

Standard Five of the NSF for Older People does not exist in isolation, and here we note three reports that contain evidence and guidance that is relevant to the material that we present later in this section, before moving on to the results of the National Sentinel Audit for Stroke, which contains the most reliable national-level information about progress with improvement in the quality of stroke services. All three reports contain evidence that policy-makers – both inside and outside the Department of Health – are aware of the importance of continuity of care, and hence of the importance of appropriately co-ordinated services.

#### **Intercollegiate Working Party**

An Intercollegiate Working Party was formed by the Royal College of Physicians. Stroke care guidelines were first produced in 1999 were updated in 2002 and 2004. The Working Party includes representatives from all

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relevant healthcare professions, social services, patients and their families. Chapter 5 of the guidelines discusses transfer to the community and discharge planning. It states that:

*The process of transferring responsibility for management from a specialised inpatient service, where co-ordination is relatively easy, to an outpatient or domiciliary service or to nursing homes and residential care homes requires considerable planning. Although this is recognised in several Department of Health circulars, insufficient attention and resources are given to the process. Discharge planning refers to any process that formally involves the team or service in transferring responsibility from one group of people or team to another.*

(Royal College of Physicians, 2004)

The guidelines contain a number of recommendations about facilitating the transition to long-term care or recovery at home, including the following.

- Hospital services should have a protocol and local guidelines to ensure that before discharge occurs:
  - patients and families are prepared and fully involved in plans for transfer,
  - general practitioners (GPs), primary healthcare teams and community social services departments are all informed,
  - all necessary equipment and support services are in place.
  - any continuing treatment required should be provided without delay by a specialist service in the community, a day hospital or outpatients' department,
  - patients are given information about and offered contact with appropriate local statutory and voluntary agencies.
- Early hospital discharge (before the end of acute rehabilitation) should only be undertaken if there is a specialist stroke rehabilitation team in the community and if the patient is able to transfer safely from bed to chair.
- Early hospital discharge to generic (non-specialist) community services should not be undertaken.
- Carers should receive all necessary equipment and training in moving and handling, in order to position and transfer the patient safely in the home environment.
- Patients should continue to have access to specialist stroke care and rehabilitation after leaving hospital.

With reference to discharge planning, the Working Party recommends that local guidelines should be developed, and that they should be designed to ensure that a smooth transfer of responsibility for each and every aspect of management occurs. This will need to cover:

- discharge protocols and documentation,
- contacting all necessary statutory organisations,
- action to take if delays occur in the setting up of community services,
- mechanisms to monitor process of handover,
- names of, and methods for contacting, all relevant local voluntary agencies.

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There is further guidance relevant to continuity of care, notably that which considers the needs of carers and families and the psychological needs of people who have had a stroke. For example, the Working Party argues that stroke services must be alert to the likely stresses on carers, and in particular recognise the stress associated with hidden impairments such as cognitive loss, urinary incontinence and irritability.

### ***What makes a good stroke service and how do we get there?***

This Department of Health report, published in late 2002 (Department of Health, 2002e), originated in a workshop which designed to identify some of the key success factors in developing a high-quality stroke service. The report aimed to provide general advice and guidance to stroke-service-implementation teams. It noted, for example, that there was a need for more training in stroke care for all clinical staff. In particular, many hospital staff did not have experience or awareness of the long-term issues that people who have had strokes have to deal with. The report observed that the clinical workforce is, as a result, geared mainly towards dealing with short-term issues.

The report supported the arguments of the NSF and the Intercollegiate Working Party that there was a need for a jointly agreed stroke care pathway defining the connections between stroke service components. It stated that these needed to be created for the long-term care of stroke patients and their carers, and not just finish at hospital discharge. The report also recognised that while many stroke services provided excellent acute and immediate rehabilitation services, it was a challenge for NHS and social care staff to address the complex and long-term problems associated with stroke. The report went on to describe how people living with stroke have highlighted the need for community services to be developed in parallel with specialist acute services and the development of outreach teams.

### ***The Stroke Association: good practice in social care***

The Stroke Association published a resource pack in 2002 for people who are responsible for the planning and commissioning of social care services for people affected by stroke. It provides guidelines for the development of long-term support, and includes a number of observations which touch on issues of continuity of care:

- Inter-agency working between health and social care organisations is essential in delivering joined-up planning and provision of services. The development of care pathways, multi-disciplinary assessment systems and single assessment processes underpin this.
- People affected by strokes and their carers require support from both health and social services. They are both entitled to have a comprehensive assessment of their psycho-social and support needs carried out by health and/or social services to provide the kind of care they want or need. Such needs should be under constant review and supported within a care management system.
- People affected by stroke and their carers should have the name of a stroke care co-ordinator they can contact for advice or to discuss changing needs, or to facilitate access to rehabilitation.

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- Social and emotional support should be provided by health and social services, including GPs, to maintain people in their own homes.
- The timely provision of aids, equipment, adaptations and personal care services, often provided on a joint basis between health and social services, helps people to stay independent.

Taking the three reports together, we can say that there is a clear concern at a national level with the co-ordination of services and a recognition of the importance of providing timely and seamless care. We can also observe that evidence about how to achieve better services is lacking, and as a result the reports tend towards general rather than specific guidance. The need for good evidence about strategies for achieving continuity of care, and the existence of a receptive policy audience, is clear.

### ***The National Sentinel Audit***

One of the positive national developments occurring in parallel with the NSF for Older People was the creation of the National Sentinel Audit by the Royal College of Physicians. The fourth round of the National Sentinel Audit of Stroke on the organisation of care was conducted in April 2004 to coincide with stroke service implementation milestones set out in the NSF for Older People. The data were collected from 256 hospitals across England, Wales, Northern Ireland and the Channel Islands between 31 March and 7 May 2004. The report concluded that, overall, there had been solid progress in the development of stroke services in England. More hospitals were offering care in stroke units and the quality of the care within the units appeared to be improving. The report expressed concern, though, that care might be deteriorating for patients managed in generic rehabilitation units. It was also noted that whereas stroke care was improving in hospitals, development of services in the community was less advanced. Some of the key findings from this round of the audit are listed here.

- Despite the 2002 Audit report stating that stroke units were of insufficient size, the median and inter-quartile range of the number of stroke unit beds was unchanged in 2004.
- Eighty-five per cent of hospitals in Northern Ireland, 82% in England and 45% in Wales reported having a stroke unit.
- A lot of work remained to improve working across the interface between primary and secondary care. Only half of the hospitals in England had established protocols for joint working.
- Two-thirds of hospitals were using selection criteria for their stroke units, apparently because they were having to ration access to them.
- There were wide variations in staffing levels between units.
- Clinical psychology services for stroke patients were still rarely available.
- Named social workers were only attached to the multi-disciplinary stroke team in two-thirds of hospitals surveyed.

### **4.2 Inter-organisational complexity and continuity of care**

#### **4.2.1 Introduction**

As was made clear in the preceding discussion of the general policy context for this study certain aspects of the inter-organisational environment significantly affect the complexity of partnership working and associated design and delivery of integrated services – whether for people with strokes or people with a learning disability. The two most important to be considered here are organisational turbulence and inter-organisational simplicity/difficulty. The former occurs at times of major organisational change – most notably in this case the restructuring surrounding health-service re-organisation in 2002. Inter-organisational simplicity/difficulty refers not just to the number of organisations responsible in any one locality for the commissioning and provision of services but to similarities or differences in their size, remit (often overlapping), resource base, history and culture. Taken together the levels of turbulence and simplicity or difficulty comprise the essence of organisational complexity as the context for delivering joined-up services. Thus, to simplify what we have said previously – and to paraphrase our original thesis – *prima facie* the likelihood of well-developed partnership working and effective service integration is greater where there is less major disruption and fewer overlapping organisational responsibilities and boundaries. Conversely, problematic partnership working and fragmented service delivery are more likely to be associated with significant organisational turbulence and a multiplicity of overlapping organisational boundaries and responsibilities between organisations differing in size, resource base and culture.

We consider these two issues across each of the three study localities. Before doing so it is worth, in parenthesis, noting one aspect of the language of partnership and joined-up working. It was apparent in interviews, as in published documents, that the phrase whole-system working is used almost entirely in a non-technical sense as a synonym for joined-up working. It is, however, not to disparage its use to describe it as largely rhetorical. In practice whole-system working comprises several elements. First, it means taking a view of service priorities and problems based on what we have previously referred to as organisational and professional altruism (Hardy *et al.*, 1992) rather than organisational and professional self-interest. In other words, a culture in which as a general rule 'your' problem in terms of service planning and provision is also 'my' problem: or, more strongly still, there are no 'my problems' and 'your problems' only 'our problems'. In this sense whole-system working represents a move towards a shared vision, shared aims and objectives and collective problems. Asked whether this was the case in South Tyneside, one senior manager said: 'yes, there is a very high belief that your problems are my problems and if you don't solve your problem it will become my problem in the end'. There is, it was said, 'a strong belief that we are all in this together no matter what our backgrounds or organisations'. According to one interviewee in South Tyneside a 'concrete example of how it's joined up' was the locality authority's decision in 2004 to use £1.2 million of the Neighbourhood Renewal fund for the PCT to employ practitioners with a special interest. This was part of the broad joint strategy for addressing the

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poor record of public health in the locality, with levels of chronic illness and early death significantly above the national average. Asked whether there was a similar sense of shared problems, partnership working and a whole-system approach in Darlington one senior service manager said: 'yes, I think so': but, he said, 'because of the sheer number of competing priorities and the turbulence within the system' there was still the need for a clearer 'shared vision about the shape of public-sector services in Darlington in 10 years' time instead of "right, you can have this and I'll have that".

From the perspective of this study it is important to note here that the huge organisational turbulence surrounding re-organisation in April 2002 coincided with the initial phase of the study. It is, of course, testimony to the openness and the forbearance of those in the study localities that they agreed the study could be conducted at a time of such upheaval. As several interviewees remarked at the time that we were negotiating access to study sites in 2002, undertaking any evaluation at such a time on the one hand risks magnifying the problems of partnership and integration – and continuity of care – precisely because it is a time of marked inter-organisational discontinuity, and, therefore, greater complexity of organisational and professional relationships. On the other hand, it was argued, a study at this time of considerable change merely exposes and throws into stark relief the problems that occur at and across organisational and professional boundaries in a field in which, after all, major re-organisation and structural change has been a fact of organisational and professional life for the past 25 years. The three case-study sites – Darlington, South Tyneside and Lancashire – were selected to reflect differing degrees of inter-organisational complexity in terms of the number (and range) of statutory authorities responsible within the localities for health and social care (see Section 2).

In view of its size and complexity it was agreed at the outset that for both tracer conditions – stroke and learning disability – we would, in Lancashire, focus upon particular localities. On the basis of discussions with local services managers and service professionals, these localities were selected to capture the complexity of service planning and delivery across Lancashire – and, it was intended, other areas of equivalent inter-organisational complexity. The specific areas chosen for the stroke service element of the project were the Fylde and Wyre Districts. They provided the added complexity that the main NHS Acute Trust provider is across the county border within the unitary local authority of Blackpool. In addition, Fylde and Wyre local-authority services relate to a further two Acute Hospitals in Lancaster and Preston. In other words – of our three case-study sites – Lancashire (and Fylde and Wyre in particular) provided the context in which there were most opportunities for discontinuity because of the huge range of overlapping professional and organisational boundaries present.

### **4.2.2 South Tyneside**

Several interviewees in South Tyneside remarked upon the extent of turbulence and organisational upheaval surrounding health-service reconfiguration in 2002. It was described graphically by one senior NHS manager as follows:

*The community services left the Acute Trust and joined the PCT. The PCG was abolished and it's work was taken on by the PCT. The health authority, which*

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*was a joint health authority, was again abolished and the South Tyneside element was taken on by South Tyneside PCT. The acute and community mental health services that were also run by the local Acute Trust were divorced from the local Acute Trust and split between the PCT and South of Tyne and Wear Mental Health Trust, who cover acute ward-based mental health across Sunderland, Gateshead and South Tyneside. And all that happened on April 1st 2002; and of course inevitably it all happened between April 1st 2002 and about April 1st 2003 before we all worked out which way was up. And it was an extraordinary year because I think every service in South Tyneside and Wear was either split or taken over or to all intents and purposes was taken over by a new organisation. The amazing thing in 2003 was that we did anything constructive while we were coping with that mayhem.*

Associated with and exacerbating this enormous organisational change was a large staff turnover. In the case of South Tyneside 'every executive officer of the PCG left in the run up to the formation of the PCT...it was picked clean of its senior PCG staff, which left a huge hole. We lost five key players in 3 months'. It is important to record the perceived effects of such organisational turbulence. More than 2 years after re-organisation in April 2002 it was said that 'even now we are uncovering things: someone will pull out a paper and say "do you know we were half way through this in 2002 and I've just realised it's got lost"'. This same interviewee continued:

*Now the crushingly urgent ones we just picked up and ran with, but there was a lot of good working across a range of issues which risked disappearing, being in limbo because of new organisations. And some things have no doubt been lost, maybe lost and gone forever; that were important in March 2002, but they just got lost.*

Even if schemes were not lost in the process of re-organisation many were significantly delayed. It was a common view across the fieldwork sites that whatever the degree of organisational change (and associated staff turnover), there was, for many service developments, effectively an 18-month period of planning/implementation blight surrounding 1 April 2002: that is, both before and after that date.

Notwithstanding the problems encountered, and apparently paradoxically, extensive organisational turbulence was said in South Tyneside to have had the beneficial effect of bringing in new staff, at senior levels and in key positions, especially across the PCT and local-authority Social Care and Health Directorate. This provided the opportunity to appoint people with a commitment to partnership working. As one PCT interviewee remarked:

*It's not only PCTs just coming into being early last year, there has also been a huge change in the council. So it's all new staff...the strength is the commitment from the new people in a partnership; so we have started together and worked together and developed together.*

A colleague in the Acute Trust echoed these views, speaking of appointing individuals with a genuine commitment to work together across organisational and professional boundaries:

*It was a case of, let's have a look at why things didn't work in the past and let's not perpetuate this system of well that's your problem not ours, let's understand each other's cultures. So it was understanding the culture from a primary-care perspective, from a social care perspective and certainly from an acute perspective: and let's see how working together we can make a difference.*



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While accepting that all this 'sounds very much like grandmother and apple pie', this interviewee's view was that the growing partnership culture at all levels across organisations in South Tyneside was of shared problems requiring shared solutions. And this, he said, has 'actually made a difference to the staff who are trying to deliver the services and, more importantly, the patients that receive them at the end of the day'. But, as this interviewee (among many others) was quick to concede, such a culture of shared problems and shared aims is inherently easier to foster where there the sort of relative organisational simplicity that exists in South Tyneside, but not in the other two study localities – and especially not in Fylde and Wyre.

As one senior health-service manager in South Tyneside put it: 'we are clear about which group of patients we're talking about when we talk to organisational partners'. He contrasted this with localities (such as Lancashire) where there are multiple PCTs and Acute Trusts in which 'the usual stumbling block is under what ratio will this be paid for...it's almost a recipe for bad feeling and it needs amazing micro-management sometimes'. So at one level it is straightforward 'clarity over who we're talking about and clarity over payment'. More generally, however, as this same manager observed 'people don't like change, so if you're dealing with a multiplicity of partners you just get an exponential growth in the potential blockages'. Similarly, the micro-management required for 'clever cultural problem-solving across many organisations again becomes exponentially complex'. Thus, he argued 'single systems, single inputs, single outputs, single pathways of care are just to be recommended every time if you can manage it'.

It was widely conceded that conterminosity – like co-location – does not guarantee good joint working and successful service integration. As one senior manager remarked: 'it's not a magic solution to be conterminous, but it certainly reduces people's elbow room to block'. So although conterminosity is not a guarantee of success 'it's certainly a building block in a system that works smoothly and well: if people are of a mind to solve a problem it's a brilliant building block'.

In its Annual Report 2003/2004 the PCT Chairman refers to the trust as 'a young and developing organisation' (South Tyneside Primary Care Trust, 2004, p.4), with a vision of improving healthcare 'by developing integrated teams of health and social care professionals' (ibid, p.2). He also describes the 'very positive relationships' with partner organisations which 'we are dedicated to continuing' (ibid, p.5). The PCT Chief Executive similarly refers to 'a strong partnership ethos here in South Tyneside' (ibid, p.8). Elsewhere, the plan refers to 'a philosophy of working together across organisational boundaries on a regular basis' (ibid, p.18). Tangible examples of this partnership working are cited. Among them are the joint appointment of a Director of Public Health and the planned pooled budget – using the Health Act 1999 Section 31 partnership flexibility – for intermediate care. The latter, it is said 'aims to improve seamless working *between all three organisations*' (ibid, p.25, emphasis added). This serves to underline the relative simplicity of inter-organisational relationships in South Tyneside as compared with areas of much greater complexity such as Lancashire.

It is important, however, to reiterate the point that conterminosity is no guarantee of good partnership working. There has to be a collective will and commitment to take advantage of such relative inter-organisational simplicity.

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An important part of the organisational context in South Tyneside has been the development of the LSP and the concurrent major re-organisation of the Borough Council. The council's own Best Value Performance Plan in 2003 acknowledged that in 2000 'we were a traditional council [which] sorely lacked direction and a mechanism for tackling our priorities' (South Tyneside Council, 2003, p.3). Following a succession of disappointing Best Value inspections the council 'decided to fully embrace the government's Modernisation Agenda', part of which included 'closer working with our partner organisations working in South Tyneside' (ibid). An 18-month period of dramatic change between 2000 and 2002 involved reshaping the organisation and management of the council itself (including the creation of a new Social Care and Health Directorate), overhauling its political structure (with the establishment of a Cabinet and Scrutiny Committee) and taking the lead in establishing the LSP in 2002.

In the space of 2 years the LSP produced a succession of documents setting out a strategic vision for the local area, with identified service priorities and targets. The most recent document, the second community strategy (*A Spirit of Change*) consolidated the previous documents into a new policy framework which sets a 10-year strategic context for the regeneration of South Tyneside. The community strategy was said by several interviewees to provide the overarching planning framework under which individual agency plans sit and within which they increasingly cohere. The council's most recent 3-year master service plan, *Performing Together* (published in March 2004), is, it is said, 'firmly grounded in the new Community Strategy developed with our partners' (South Tyneside Council, 2004, foreword). This sets out the same key objectives referred to in the community strategy under the broad area of healthy living and care, one of which is to reduce cancer, heart disease, strokes, diabetes and mental illness.

One of the most obvious advantages of conterminosity, according to many interviewees, was the straightforward logistical one of being able to meet regularly, both formally and informally, at all levels of organisations. It simply makes service planning easier. In South Tyneside, for example, there is a single set of joint planning forums. There may still be different agency planning requirements but there is not a need for duplication or triplication (or worse) of joint structures as there is in a local authority such as Lancashire, with eight PCTs and four Acute Trusts. Communication was the most frequently cited advantage of conterminosity: being able to discuss proposals or problems with a small number of people – and with the same group of people. In South Tyneside, for example, there were regular meetings at chief executive and director level between the Acute Trust, PCT and the local-authority social care and health directorate. They were said to 'work very closely together in a very integrated way: it's a very integrated structure'.

One important practical advantage of conterminosity cited was a lessening of the problem of differences in service according to 'those invisible boundaries that often run down streets'. And in these cases the recipients of patient complaints are, it was said, 'the staff at the sharp end' with 'more and more complex delivery modes'; for example, taking equipment to one patient but not the near neighbour on the other side of the street and 'trying to explain what to most people is just NHS mumbo-jumbo'.

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Another simple practical advantage of organisational conterminosity was that co-locating staff is easier. In South Tyneside there is extensive and increasing co-location of senior local authority (social care and health) and PCT staff. Although 'they already meet regularly together, it'll be taking it one step further in ensuring that they have got that ongoing working relationship'. Thus, in respect of communication, 'with the best will in the world if you're in different buildings it's hard to have that ongoing communication – just bumping into people in the corridor in the same room. It's making sure that communication is linked up, even at the smallest levels rather than having everything formal meetings'.

### **4.2.3 Darlington**

In the case of Darlington the organisational turbulence surrounding the creation of PCTs and Special Health Authorities in April 2002 was magnified by several other related factors associated with the acute services review undertaken by Professor Ara Darzi. Professor Darzi (Professor of Surgery at Imperial College London) was commissioned in December 2001 by County Durham and Darlington Health Authority to review services at the four acute hospitals within the area; Darlington Memorial Hospital, Bishop Auckland General Hospital, the University Hospital of North Durham and Shotley Bridge Hospital. The review was extremely rapid, with the report produced in February 2002.

Professor Darzi referred to a context of historic under-investment in local health services, health status poorer than the national average and acute hospitals each serving small catchment areas. His view was that the hospitals would struggle to meet increasing demands and provide better-quality care unless they worked closely together. Only the latter would ensure the hospitals a 'robust and vibrant future' (Darzi, 2002, p.3); it is, he argued, 'the interdependence between all the hospitals that is the basis of the way forward' (ibid). Given their size (557 beds at the University Hospital of North Durham, 423 beds at Darlington Memorial Hospital and 347 beds at Bishop Auckland General Hospital) Darzi's strictures about joint working were aimed especially at these three main acute hospitals. The 'key to any way forward', he said:

*...is for the staff in all three hospitals to develop an understanding of the interdependence of the work between all three sites...it will take some time before all the staff move away from thinking dominated by the interests of their own unit. But it is clear that none of the sites will thrive unless they are all linked and staff are working together to serve the needs of the people of the whole area.*

(ibid, p.10)

He concluded by underlining the importance of this collective recognition of independence and the need to develop the arrangements which would 'enable all sites to work more collaboratively' in providing county-wide services (ibid, p.18). Darzi's emphasis upon the need to recognise interdependency and partnership was due not solely to the hospitals' small catchment populations but also to important national changes in clinical practise: increasing specialisation of services, reduced hours for hospital doctors and the need for a critical mass to sustain clinical training. A central element in his recommended new way of working was the development of clinical networks.

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Such networks, he said, were 'not well developed across the county' and were even patchy within the same trust (ibid, p.6). Although some support services were already working across the county to some extent – pathology, imaging, and ambulance and patient transport – there was, Darzi argued, the need 'to develop more explicit whole county solutions' (ibid, para 73, p.16). It should be said that several interviewees in this study argued that there was an inherent problem, if not contradiction, with Darzi's recommendations for the development of managed clinical networks and for a pan-Durham Acute Trust. As one remarked: 'the problem with Darzi is that the clinical networks that exist outside of this organisation are split [north and south]; and one of the lessons from any merger is don't disrupt your clinical networks...it's complex, you can't disrupt clinical networks outside your organisation'.

Given the timescale Professor Darzi's report and recommendations were of a necessarily high level. The subsequent detail, fleshing out his recommendations, was laid out in the report *Access, Choice and Sustainability*, produced in April 2002 (County Durham and Tees Valley Health Authority, 2002). This report not only endorsed the strategic vision for acute services outlined by Professor Darzi but provided the basis for statutory consultation (a) on the detailed service changes involved and (b) on the principal organisational change Darzi proposed: the merger of North Durham and South Durham and Darlington Trust into a single county-wide Acute Trust 'as quickly as possible' (ibid, p.3). The report referred to the overall aim of providing greater choice to patients and increasing hospitals' capacity. The proposed changes placed 'a strong emphasis on new ways of working with improved collaboration and co-operation, a development of networks and greater specialisation' (ibid, p.5). The document also noted that notwithstanding its focus on acute hospital services 'there is full recognition of...the necessity for whole systems working in order to ensure the effective delivery of acute services' (ibid, p.6); 'the greater role of partner agencies in the provision of health care' (ibid, para 1.5.6) and 'the need to make best use of the limited availability of key medical, nursing and therapy staff' (ibid, para 1.2.7). The report refers to the national trend towards centralisation of services, with 'concentration of scarce skills in teams dealing with specific conditions, e.g. stroke, diabetes, cancers' (ibid, para 1.2.4). The report's proposals made it clear that the top priorities were not stroke services but the reconfiguration of obstetrics and gynaecology, child health and general surgery. The proposals for stroke services are set out in the following five paragraphs (ibid, paras 2.4.7.1–2.7.5).

- *It is proposed that a specialised inpatient service is the way forward and to improve stroke patients experience. Currently, patients at Bishop Auckland General Hospital are managed by a specialist team in a dedicated area, which improves their rehabilitation outcomes. At Darlington Memorial Hospital, the inpatient stroke service is part of an acute medical ward. It is proposed that all acute stroke admissions in South Durham and Darlington would be directed to Bishop Auckland General Hospital and be managed as a single service by dedicated physicians with a specialist interest in stroke management.*
- *The transfer of staff from Darlington memorial Hospital would support the single inpatient acute unit.*
- *Outpatient services would still be provided at each site.*
- *There is a commitment to the local development of a stroke unit for the population of North Durham.*

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- *A strategic review of stroke services is currently underway across County Durham and Darlington and will be completed by the summer. To deliver the NHS Plan targets will require an increased amount of a number of beds or a significant investment in intermediate care to support the rehabilitation of those who have had a stroke in community or domiciliary setting.*

It is worth noting that in the subsequent consultation period the proposal to centralise acute stroke services at Bishop Auckland was not challenged.

Although, as one senior service manager remarked, it was 'a bit numbing' for staff in Darlington; and, she said, 'left our stroke planning in a limbo'. Finally, in relation to all services the consultation document sets out a list of 11 aims and goals in relation to quality care, including (ibid, para 3.8.1):

- *to help a move from hospital to primary care/community care/social care;*
- *to ensure that patients experience seamless care from all agencies would provide different aspects of care and support services e.g. primary care, acute care and social services.*

The new single Acute Trust would, it is said, continue to seek to achieve this by, *inter alia*, 'working in partnership with other agencies to ensure continuity of care' (ibid, para 3.38.2).

Throughout the document there are references to the importance of interdependence, partnership and service integration: the need for 'strong whole systems working across primary and community care together with partner agencies to deliver the vision'. This is said while noting the simultaneous re-organisation of primary care – with six PCTs (three in South Durham and three in North Durham) – established on 1 April 2002, just prior to the document's publication. This is noted, however, without explicitly acknowledging the extent of the challenges involved in such a major re-organisation of acute care (in late 2002) on the heels of major re-organisation of primary care only 6 months earlier. This series of significant organisational discontinuities was, however, part of the complex context within which service managers and professionals in Darlington were working throughout our fieldwork period. It should be said that notwithstanding the complexity of the context – and the difficulties outlined here – there was evidence of growing partnership working locally. Thus, in a Joint Review of Darlington Social Services by the Audit Commission and Social Services Inspectorate in July 2002 the Council was 'commended on its determination to work in partnership with other organisations' (Joint Review Team, 2002). According to the Joint Review Team partnership working was one of social services' 'key strengths' (ibid, p.73). The team noted Darlington's small size (the fifth smallest social services authority in England) but said that one of the advantages of small size was 'that informal as well as more formal partnership working can be established. Darlington has capitalised on this and has established cordial and effective working relationships with Health partners' (ibid, p.23)

However good these relationships, as the Darzi report made clear – and, indeed, as had been acknowledged before Darzi – stroke services within Darlington could not effectively be jointly planned, commissioned and provided from within Darlington – they had to be planned on a South Durham and Darlington or on a county-wide basis: that is, not simply via Darlington PCT, Darlington Borough Council and Darlington Memorial Hospital working together (as is the case in another of the localities in this study, such as

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South Tyneside). In commissioning and providing services Darlington PCT must work as one of three South Durham PCTs and one of six county-wide PCTs: and the Memorial Hospital must work as one part of a county-wide Acute Trust and, over time, of a county-wide set of services, stroke included.

Whereas the need for partnership working based on close interdependence was clear and widely accepted, the complex organisational context – as was frequently underlined by interviewees – made strategic and operational planning for stroke services extremely difficult. In the case of stroke services the 'whole system' extended beyond the boundaries of the Darlington authorities: therefore, unlike South Tyneside, any joint commissioning and integrated provision require partnership working across neighbouring agency boundaries, not simply within Darlington itself. Although there was what was described by one interviewee as 'a well-functioning Local Strategic Partnership' – launched by the Prime Minister in 1997 – a Partnership Board for Older People was still being developed at the conclusion of our fieldwork in 2004. In April 2003 Darlington Partnership published a community strategy (Darlington Partnership, 2003). Describing the strategy as 'an opportunity to truly join together to achieve our shared vision for the borough [providing] an overarching framework for all plans and strategies of partner organisations...it should ensure we are pulling in the same direction, collectively working towards our shared goals' (ibid, p.4). While noting that 'local NHS services have been undergoing major reform in recent times' (ibid, p.38) the strategy speaks optimistically about many of the area's services being conterminous with the unitary Borough Council, 'which makes for effective joint planning and delivery of high quality services' (ibid, p.10). Many other services, however, including a wide range of health services, are not conterminous. One notable example is stroke services, the joint planning for which over several years been done on a sub-regional basis – across South Durham and Darlington. The Darlington Community Strategy says bluntly that 'partnership working is at [its] core' (ibid, p.4); however, in the case of stroke services, as indicated above, partnership working and planning was, and is, required across a much wider network of organisations outside the boundaries of the borough. Unsurprisingly, given the degree of inter-organisational complexity, turbulence and change, stroke services during our study – from late 2002 to late 2004 – were variously described by several interviewees as appearing in many respects 'unplanned' and 'unco-ordinated'. There were, however, concerted attempts to plan those services across this rapidly changing and uncertain environment.

The production of a draft stroke strategy was begun in October 2001 but 'got subsumed' by the Darzi Acute Services Review. The South Durham plan for specialist stroke services was eventually published in August 2003. It was written on the basis, post-Darzi, of the development of Bishop Auckland Hospital as the centre for stroke services in South Durham. The plan set out proposals for a specialist service 'which the NSF requires to be implemented by April 2004' (South Durham Health Care NHS Trust, 2003, p.3): that is, to be implemented only 7 months after the plan's publication. The Darzi proposals – endorsed in the subsequent report *Access, Choice and Sustainability* – and the NSF for Older People (Standard Five) together comprised the strategic context within which the plan was written. It spelt out not only the need for the investment required to develop a specialist stroke service but the components of such a service. In line with the NSF the plan

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refers to the need for a specialist stroke team, led by a clinician with expertise in stroke, and lists the professions which comprise such a team: medical, nursing and therapy (physiotherapy, occupational therapy, and speech and language therapy) input together with dietician, clinical psychologist, pharmacist, social worker/family support and stroke care co-ordinator. Indeed, the latter, it is implied, is additional to a clinical specialist nurse. Such a team would represent a significant addition to existing resources. As the plan makes clear, the only specialist resource at Darlington was a 0.7-whole-time equivalent (wte) F-grade stroke specialist nurse. The therapists (occupational therapy and physiotherapy) working on the six stroke beds 'are part of general department staffing and are not resourced specifically for stroke services' (ibid, p.8). Similarly, there was no specialist speech and language therapy service for stroke; instead patients – at both Darlington and Bishop Auckland – had access to a speech and language therapist (SALT) with specialist knowledge of acquired neurological disorders (of which stroke is one). But a speech and language therapist did regularly attend MDTs of the stroke programme at Darlington Memorial Hospital. This was not the case for clinical psychology – the service described as being for all practical purposes non-existent: that is, there was a clinical psychologist working one afternoon per month for the whole of medicine. Staff had long since ceased to even make referrals to this service. This is a direct echo of the position in Lancashire – although here referrals continue to be made, not least to underline the effective absence of a service. It is also a marked contrast with the position in South Tyneside where a clinical psychologist worked half-time on the Stroke Rehabilitation Unit and regularly attended the stroke-unit MDTs.

In line with the proposals set out in *Access, Choice and Sustainability* the plan is built around the proposal that all acute admissions be to Bishop Auckland General Hospital; to be treated, as a single service, by staff with a specialist interest and expertise in stroke management. The plan also cites the Darzi strategy's recognition 'that to deliver the NHS Plan targets will require an increase in either the number of beds or a significant investment in care to support rehabilitation...in community or domiciliary settings' (ibid, p.5). The Plan notes simply that 'there are currently no stroke dedicated rehabilitation teams or facilities in South Durham and this is seen as a major area requiring development' (ibid, p.7). The plan described the existing hospital-based provision as comprising 'specialist stroke teams and beds on each hospital site' with 17 'dedicated stroke beds' at Bishop Auckland Hospital and six such beds at Darlington Memorial Hospital. Whereas the beds at Bishop Auckland Hospital are within a single ward providing 'mixed acute care and early rehabilitation', the six beds at Darlington Hospital are within a general medical ward and the stroke team 'provides rehabilitation based care'.

The plan's proposed service model is couched in terms of a vision 'to provide a patient-centred stroke service which is integrated between all care provider organisations' ensuing the delivery, *inter alia*, 'of seamless and integrated care between secondary, primary and community care settings and NHS providers' (ibid, p.10). The single-site acute stroke unit at Bishop Auckland Hospital would provide care during the acute phase and early rehabilitation. Ongoing rehabilitation (after 2–3 weeks) would be provided 'by locality based community stroke rehabilitation teams who would provide domiciliary rehabilitation for all patients assessed able to benefit from this'. Such teams

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would be integrated with both the acute stroke unit and the emerging intermediate-care services within each locality; they would, among other things, 'ensure continuity of care' (ibid, p.11). Those requiring longer-term bed-based rehabilitation would receive this in a range of community hospitals, intermediate-care beds and private-sector (care-home) beds.

It was suggested that this specialist stroke service be phased in over 3 years; this in a context in which, it was said, the whole of the Darzi timescales had quickly slipped because of the scale of the investment involved across acute services as a whole. Year one (2004/2005) would see the development of the community-based specialist stroke rehabilitation services. This would require three senior 1 physiotherapists, three senior 1 occupational therapists, 10 wte therapy assistants, one full-time senior dietician, a 0.5-wte dietetic assistant, one full-time SALT and one full-time secretary. The total outline revenue costs (excluding travel costs) for this staffing were £413 600. No estimate was given for associated capital/equipment costs. In year two (2005/2006) the proposed developments included a rapid-response assessment and information service for patients presenting with minor strokes and transient ischaemic attacks (TIAs; at both Darlington and Bishop Auckland) and the provision of a stroke clinical information system. Associated costs covered further staffing: a consultant physician based at Bishop Auckland, a full-time secretary to the consultant and a full-time stroke co-ordinator. Total outline revenue costs here were £137 400. In addition there were small costs associated with clinical infrastructure (£6000) and assessment and imaging equipment – for duplex and CT scanning (£12 000). In year three (2006/2007) the plan was to transfer acute stroke beds to the single site at Bishop Auckland General Hospital – with an estimated 30 beds required; although it was anticipated that this figure would be lower due to the year one and year two service developments. Here the outlined staff costs were again considerable. Proposed additional staffing comprised: 12.15 wte nurses (seven A grade, three D grade and 2.15 E grade) at £242 000, one full-time SALT, one full-time consultant psychologist, a 0.5-wte senior 1 dietician, one full-time dietetic assistant, two full-time basic-grade psychotherapists, two full-time senior 2 physiotherapists, two full-time basic-grade occupational therapists, two full-time senior 2 occupational therapists, eight wte therapy assistants and one full-time secretary. Total revenue costs were £692 445. The total outline investment over 3 years was thus £1.26 million. The plan's conclusion refers to the need for this 'significant investment over a sustained period' in order 'to develop a specialist stroke service which meets the needs of patients during both the acute and rehabilitation phases of their care' (ibid, p.17). This was recognised by one of the principal architects of the plan as 'a very expensive proposal'. But it was expensive, it was widely agreed, because the plan's authors were 'trying to rectify historic under-investment in stroke services'.

After what was described by one interviewee as 'a lengthy gestation period' the draft plan was 'signed up to by all the parties'. Although, as other interviewees argued, this was not a formal signing up: according to one, in mid-2004 the plan had 'been discussed in a lot of forums, but not formally adopted by anyone'. Nevertheless it was in various ways endorsed.

In its first Local Delivery Plan (LDP; for 2003/2006) Darlington PCT spelt out its three main priorities as: access, meeting NSF/NHS plan targets, and



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financial balance. The LDP refers to 'significant financial implications in delivering the older person's agenda' but sets out a number of 'key deliverables'. These include 'reducing emergency admissions; single assessment; and implementing both the diabetes NSF and the local stroke services plan' (Darlington Primary Care Trust, 2003, para 9). The LDP concludes, however, by referring to 'the enormous tensions between available resources and stated aspirations' (ibid, para 10).

These tensions became evident throughout the fieldwork for this study as local service managers and service professionals sought to implement the planned changes in this context of enormous organisational complexity and what was described by one senior manager as 'a limited amount of resource'. Thus, while readily acknowledging 'the unprecedented inward investment over the last 3 to 4 years...the expectation of so many central plans is that you have got to do everything about implementing everything'. As indicated above, this complexity is, in essence, dual-faceted: it is a product of severe organisational turbulence – principally around PCT and Acute Trust reconfiguration – and of the multiplicity of stakeholders, each with differing pressures and service priorities. 'This is', as one senior manager simply remarked, 'a turbulent time...the environment isn't as conducive to longer-term strategic planning that it might otherwise be when it's a bit more stable'. This, it was stressed, had a significant impact at the operational level of service delivery: among other things 'you can easily get people retrenching because of the uncertainty and that's a natural reaction'. More, importantly, in the view of one senior clinician (among others) the Darzi report (Darzi, 2002) – or rather the period of consultation and uncertainty associated with the Darzi report – in conjunction with the significant upheaval associated with other major structural changes, caused a degree of planning blight upon local service development: 'it undoubtedly did because the inpatient stroke specialist beds would be located at Bishop Auckland, therefore it wasn't going to be appropriate to develop a parallel service down here [in Darlington]; development of the service is on hold here effectively'. There had, it was said, been a 'burst of enthusiasm' and plans to develop stroke services in Darlington in the late 1990s, but that development and investment wasn't going to be made until the Darzi proposals were implemented – and even then this would be investment outside Darlington itself. In the meantime – while the plan was to move specialist services to Bishop Auckland – there was no chance of increased investment in, for example, therapy staff for the stroke rehabilitation programme.

*All we have been able to set up is the TIA clinics and a sort of stroke rehabilitation service. So what we are missing is the stroke unit and the appointed entry into the stroke service because that is still part of the general medical activity... So until the patients are stable enough to be seen they don't receive any specialised stroke services, they receive normal physiotherapy and occupational therapy. And there is no doubt whatsoever that is a defect in the service.*

This planning blight had an effect in many ways at the operational level. One example given was the development at Darlington of a single patient record. This was something which was not done, or was not done as quickly because of uncertainty about the future: 'you think if you put a lot of work into it the time comes when they say "this is all going to go over to Bishop Auckland"; then a different one would be devised'.

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As elsewhere in this study, interviewees underlined the significant extent and effects of such organisational upheaval upon service development and delivery; many in PCTs arguing that 15 months after their establishment, trusts were still to finalise their re-organisation – and even, in some cases, still to finalise senior appointments. Even then they remained young organisations finding their feet. As one senior manager remarked in April 2004: 'the changes across the last 2 years – County Durham mergers, consultation reports, PCT establishment, we are still in our infancy – just trying to put structure in place. Its bedding down now'. The reconfiguration of the Acute Trust added yet another layer of complexity; with, for example, newly appointed planning staff trying to knit together what previously were separate parts of the county and separate stroke services. As one senior service manager remarked: 'such organisational change slows you down [not least] because inevitably a lot of management staff left the organisation'. In particular with 'changes in senior planning personnel', stroke services planning for a period around re-organisation in 2002 'dropped into a bit of a black hole'. And overlaying this complexity was the Darzi proposal to reconfigure stroke services by centralisation at Bishop Auckland.

Speaking towards the end of our fieldwork in May 2004 one senior Acute Trust manager said:

*...everything you read about mergers, integration, re-organisation [is that] they put organisations back. That's what has happened here...we lost the executive team...everybody has got to start and work together: that takes months, years even.*

In her view the merger of the two Acute Trusts 'has made it more complex for stroke altogether...it was much easier north and south, it has made it much more complex'. She could, she said, 'see a better service for patients, but I can't see it for some time yet'. And one reason, she said, why the stroke service plan had still not been implemented in late 2004 was 'because it is extremely expensive'. Another reason, she said, was that newly constituted PCTs faced with a range of competing priorities for investment and faced with such a large investment in stroke services took the view 'that we can't afford this': they would agree to invest in community services but could not afford to develop the hospital services. In fact within Darlington PCT there was a clear acceptance of the need for investment in specialist stroke services, both acute and community. As in initial investment, £75 000 was made available in 2003/2004 for increased therapy staff – occupational therapy and physiotherapy – 'and to start developing our community rehabilitation service around stroke'. But the full scale of the requisite investment would become clear, it was emphasised, only upon conclusion of a set of strategic discussions (between the PCTs and Acute Trust) about the number, location and size of acute units and the appropriate model of community services. It was also clear that one of the principal issues for Darlington PCT was the concern that if it was going to be a county-wide resource, investment in acute stroke services at Bishop Auckland Hospital should be not just by the three South Durham PCTs – as envisaged in the plan – but by all six County Durham and Darlington PCTs.

Acknowledging that it was a bit pessimistic, the same manager said that with three relatively small district general hospitals there was a need for service managers and service professionals to acknowledge that it isn't possible to

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have three separate acute stroke services but to see it as one total stock and one service: 'that's where we have got to get to...but not everybody is thinking like that'. The other pressing need, she said, was for all those concerned to accord stroke services a much higher priority (see below).

Towards the end of our fieldwork period in 2004 discussions were taking place about broad strategic options: whether to have one stroke unit for the whole of Durham and Darlington (at Bishop Auckland), or to have two units – in North Durham and South Durham (the southern unit, again, being in Bishop Auckland), or – a less likely option – to have three units (in North Durham, at Bishop Auckland and at Darlington). The emerging consensus at that time was that there should be two stroke units: in Bishop Auckland for South Durham and Darlington and in Durham City for the north of the county. This, however, was a strategy that had to be fully developed and costed.

Irrespective of which of these strategic options was adopted, the near-certainty will be that in future Darlington residents who have a severe stroke will go to Bishop Auckland for the acute phase of their treatment and initial rehabilitation: that is, roughly the first 2–3 weeks after hospital admission. Thereafter, however, as the stroke service plan made clear, there would be a need for provision of more localised, long-term intensive rehabilitation for an average of 3–4 months. It was generally thought that Darlington residents would willingly – even if not with universal approval – travel the 12 miles to Bishop Auckland for specialist acute hospital treatment. What was less likely to be acceptable was the prospect of families and carers travelling that distance for a lengthy period of rehabilitation: and, as one interviewee remarked, 'I don't think the patients will be too keen about that'. Without any community hospital beds in Darlington there was therefore another set of strategic decisions to be taken about where to locate intensive, post-acute rehabilitation. This could, it was said, be to Darlington Memorial Hospital with, effectively, an extension of the current stroke rehabilitation programme beds, or to the new intermediate-care beds at Hundons Lane, or to independent-sector care-home beds. Whichever option was chosen – anticipated to be some combination of the above – there were acknowledged to be 'important issues about moving people who have had a stroke [because of] their confusion'. It was, therefore, important for patients to be as near to home as possible for social support and 'not moved around in lots of different establishments'. According to the same service manager:

*They need to come back somewhere they know, and carers and families know, that this is the place where they are going to be until they are able to either go home or make some longer-term plans.*

Another part of this set of strategic discussions in 2004 between the PCTs, Acute Trust and local authorities (in and around Darlington) focused on the nature and level of investment required to staff the community stroke service. The issue of whether there should be a specialist stroke service or whether this should be provided from within a general community rehabilitation service was yet to be agreed; although there were said to be a recognition among many managers and service professionals that stroke 'is a slightly different area because of its complexity'.

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### **4.2.4 Lancashire: Fylde and Wyre**

As indicated above, the case-study areas of Fylde and Wyre are two of the 12 Local Authority Districts (including the City of Preston) covered by Lancashire County Council. They have populations of around 74 000 and 106 000 respectively out of the 322 778 living in Blackpool, Fylde and Wyre as a whole and the approximately 1.4 million living in the entire Lancashire LSP area (Office for National Statistics Population Estimates 2002; [www.statistics.gov.uk/census/default.asp](http://www.statistics.gov.uk/census/default.asp)). At approximately 6%, the ethnic minority population of Blackpool, Fylde and Wyre is relatively small compared with other areas in Lancashire such as Blackburn with Darwin or Burnley (Office for National Statistics Census 2001). In terms the older population, Fylde and Wyre PCTs commission and provide health services for 40 125 older people (among a total patient population of 199 371), with 16 720 in Fylde and 23 405 in Wyre. In addition, Lancashire Social Services supports over 1800 older people in Fylde and Wyre through a variety of services. Figures specifically for stroke were not readily available at the time of our fieldwork.

The Fylde and Wyre areas comprise numerous inland towns and villages, from Kirkham and Wesham in the south east nearer Preston, to Garstang in the north east nearer Lancaster and Poulton-le-Fylde near Blackpool itself. There are also seaside resorts, from Fleetwood, Thornton and Cleveleys on the coast north of Blackpool (Wyre District) to Lytham and St Anne's to the south (Fylde District). All of these areas are seen as very different from each other in terms of character and economic affluence, and the fact that they are geographically dispersed with relatively inconvenient public transport links is an issue for patients travelling between the many different hospital locations across the area. Blackpool is a separate unitary local authority, which is not part of the case-study area for this research. However, as will become clear the service commissioning and provision arrangements relevant to continuity of care for stroke patients are inextricably linked across the Blackpool, Fylde and Wyre area as a whole.

Blackpool, Fylde and Wyre Hospitals NHS Trust, which was formed in 2002 from a merger of separate acute and community NHS Trusts, serves a local population of approximately 330 000 Blackpool, and Fylde and Wyre residents plus the area's 16 million annual visitors. It has a total budget of around £165 million per year, and manages:

- Blackpool Victoria Hospital, a large acute hospital;
- five smaller community inpatient/day hospitals at Clifton, Lytham, South Shore, Devonshire Road and Fleetwood; and
- three elderly rehabilitation units operated as private finance initiative (PFI) sites at Wesham, Rossall and Bispham.

The trust also manages the National Artificial Eye Service, and Blenheim House Child Development Centre, and is one of four tertiary cardiac centres in the north west, providing specialist cardiac services to heart patients from Lancashire and South Cumbria. Across its multiple sites, the trust employs 4400 staff, has approximately 1195 beds and sees more than 85 000 day-case and inpatients, 300 000 outpatients and 85 000 accident and emergency (A&E) patients every year. Table 1 summarises the Trust's sites relevant to stroke patients at the time of fieldwork in 2004. As the table shows, the strategy is to handle patients in the acute phase of stroke at

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Blackpool Victoria Hospital. Patients are then transferred to the specialist rehabilitation facility at Clifton Community Hospital if they are considered suitable (i.e. likely/motivated to benefit from intensive support), to the other general rehabilitation wards at Clifton or the remaining community units.

**Table 1 Location of stroke care across Blackpool, Fylde and Wyre Hospitals NHS Trust**

Acute care	Community hospital rehabilitation (inpatient peripheral beds)		Day services and outpatients'
Blackpool Victoria Ward 20 (Acute Stroke Unit) has total 18 beds. The preferred route onto ward 20 is straight from A&E and/or medical assessment unit. However, patients still go onto other medical wards (e.g. gynaecology, diabetics, etc.) due to lack of beds on ward 20 (i.e. not covered by stroke consultant) and may or may not be transferred. In addition, non-stroke patients come onto ward 20 if they need barrier nursing because it has side wards.	Clifton Hospital, at Lytham St Anne's  Directly managed by trust: total 92 rehabilitation beds, 20 of which are on ward 2/Gloucester Unit, which is the stroke/neuro rehabilitation unit (i.e. currently has non-stroke patients). Stroke patients also go onto other elderly rehabilitation wards (i.e. not necessarily designated for stroke consultant).	Wesham (40 beds)  Bispham (40 beds)  Rossall (40 beds)  Patients are transferred from Blackpool Victoria to any of the PFI elderly rehabilitation units depending on bed availability and patient preference. Sites tend to have consultants dealing with general older people's care.	Clifton has a day hospital, with referral straight from Blackpool Victoria (if patients are going home without community hospital inpatient care) or after discharge from Clifton.  Among the PFI sites, Rossall and Wesham have day hospitals, but Bispham does not.  Southshore Hospital has a SALT half day club that runs weekly from September to July specifically for stroke patients. There are 20 places and patients come via several routes: GP, self-referral, or referral on discharge by any therapist in the Blackpool, Fylde and Wyre area.  Patients may also return to Blackpool Victoria for outpatients' follow-up with medical consultants and/or stroke specialist nurse, etc.

Interestingly, ex-stroke patients from Blackpool and Fylde and Wyre may also request a referral to Kirkham Prison for gym coaching/additional physiotherapy after they have been discharged by the NHS. The route is via GP referral, but not all GPs are willing to send patients to the prison for this service – although the service has a strong reputation with patients and was even highlighted in a local newspaper article in early 2004.

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As already noted, the particular geography of the area (i.e. varied hospital locations and distances between them) is a major issue not only for the local health system but for patients and families in Blackpool, Fylde and Wyre. Patients are sent from Blackpool Victoria to any of the PFI sites depending on bed availability. The other factor is home address for ease of family visiting (e.g. Rossall is in Fleetwood in the north of the area, at the opposite end to Clifton in the south; and Wesham is on the M55 towards Preston). Also, if not discharging to Clifton, ward 20 at Blackpool Victoria usually tries to refer to Rossall because it has a day hospital for subsequent outpatients. Bispham tends to get sub-acute patients and rarely gets strokes because it is always full and has no day hospital. One of our staff interviewees from Rossall Hospital summed up the situation as follows.

*We do get some stroke patients, but with Clifton being the stroke rehabilitation, if they haven't got beds then we do tend to get the ones that there isn't beds for. Or geographically, because of the distance between Rossall and Clifton, if you live in Fleetwood, if you have not got your own transport it is horrendous trying to get to Clifton Hospital, so sometimes they will suggest that we take somebody because of visiting facilities if nothing else.*

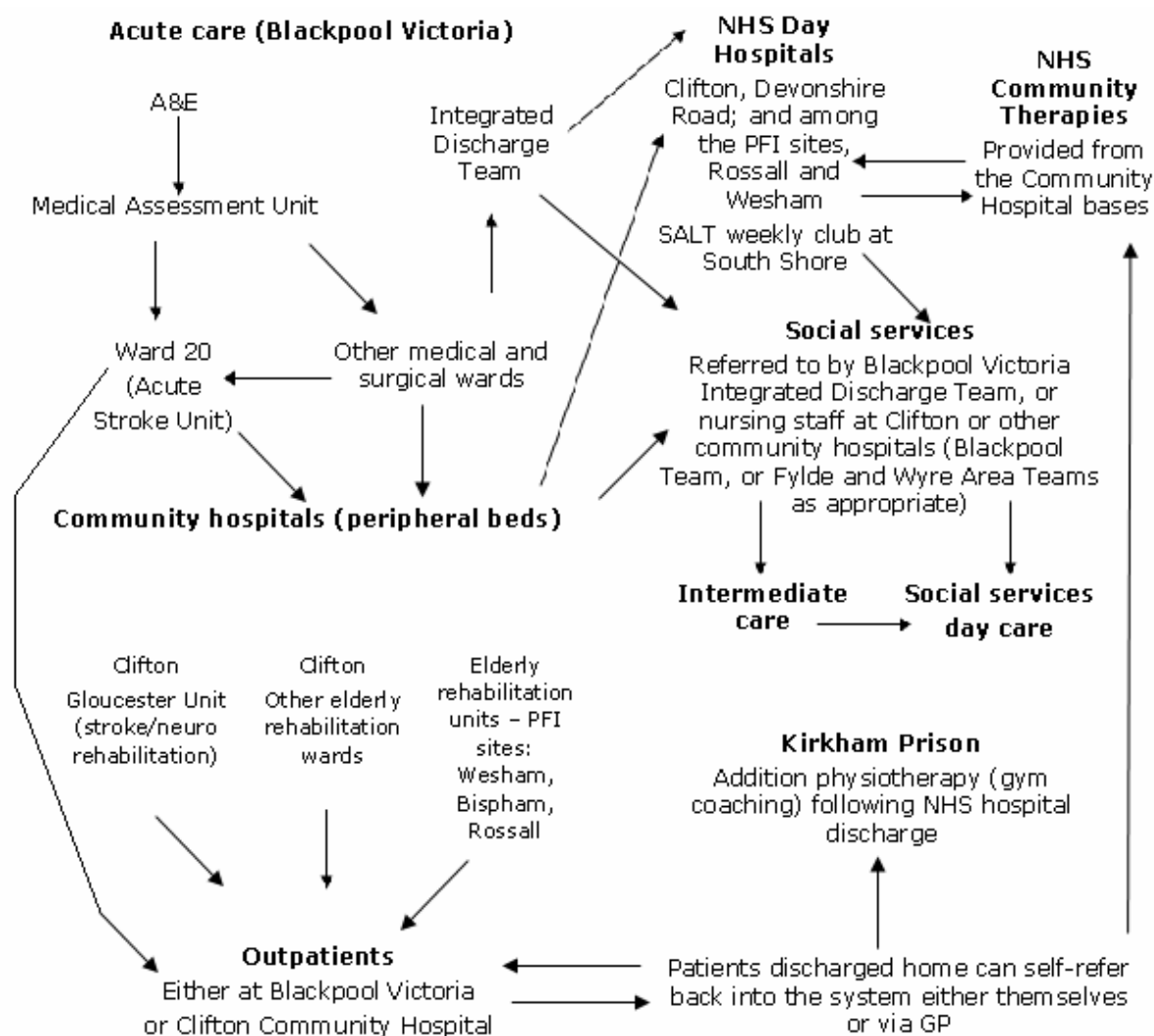
The complexity of the stroke service system in this part of Lancashire is illustrated in Figure 1 (overleaf).

In terms of the complexity of the health and social care system locally it is also relevant that, as part of Lancashire County, our case-study area of Fylde and Wyre receives patients discharged from acute hospitals in Preston and Lancaster in addition to patients from Blackpool. Both of those areas are less well served in terms of the availability of rehabilitation beds than the Blackpool area (due to the different legacies of trust mergers, etc.), which according to social service interviewees impacts on their likely care pathway because: 'it may be there would be a request sooner from the acute setting for a placement in residential care or nursing care from either Lancaster or Preston'. As the interviewee asked, 'Does that make sense?'

In addition, Blackpool, Fylde and Wyre Hospitals NHS Trust discharges patients to the unitary local authority of Blackpool itself. An interviewee at Blackpool Victoria Hospital described the complex partnership arrangements that this requires in the context, for example, of hospital discharge.

*The packages that we [Integrated Hospital Discharge Team, which works across Blackpool, Fylde and Wyre] put in come under intermediate care and they are actually free of charge to the patient for the first 10 days. That was agreed between Blackpool and Lancashire because what we cannot have is, whereas a Blackpool resident has five days a Lancashire resident has 10 days. Before the end of that 10-day period they would be reassessed by the community social worker... [But] you can't actually go by postcodes [for social work referral]. Because you can have an FY5 postcode, which is technically Wyre, but when you get going out of Blackpool and you sort of go from Anahome through to Thornton Cleveleys [north of Blackpool], there is a lot of people in that area, even half the street could be Blackpool and half could be Lancashire. So we always make sure if they live in that kind of area or anywhere very south of Blackpool edging on towards Lytham, we always ask 'Where do you pay your council tax?'. Because once you have made that mistake it's so difficult then because you get involved with accountants, and what you have is, because you put this social care package in is, 'No, it's not that one it's Lancashire, Lancashire should be paying for it.' So it's important we get the correct area.*

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**Figure 1 Potential routes through the health and social care system in the Fylde and Wyre case-study area**

Arrows indicate possible referral/discharge routes. SALT, speech and language therapy.

Blackpool, Fylde and Wyre Hospitals Trust relates to two separate PCTs – Fylde PCT and Wyre PCT – providing primary-care services in the case-study areas. These PCTs are conterminous with their equivalent local-authority districts delivering housing services. There is also a third PCT in Blackpool that is conterminous with Blackpool unitary authority. Despite being entirely separate, the three PCTs have attempted to commission many of their services (e.g. equipment) on the basis of joint arrangements across all three organisations. At the time of the fieldwork (early 2004), however, these arrangements that had been led by Blackpool PCT were being restructured. In addition, the three PCTs retain separate local commissioning structures for other services (e.g. allied healthcare provision), with commissioning decisions and priorities being made on the basis of organisation-specific assessments of their population needs. As will become clear later in the report, this only serves to add to the complexity in terms of designing and delivering services locally.

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In terms of service provision relevant to stroke, Wyre PCT takes the lead as host organisation for (a) the Joint Equipment Store the operates across all three PCTs, Blackpool Social Services and Fylde and Wyre Social Services, (b) the employment of most of the allied health professionals (physiotherapists, occupational therapists, SALTs and dieticians) based in the various Blackpool, Fylde and Wyre Hospitals Trust sites (Blackpool, Fylde and Wyre Hospitals Trust itself employs only the physiotherapists based at Blackpool Victoria Acute Hospital) and (c) the employment of the community physiotherapists, SALTs and occupational therapists who provide NHS care once patients leave hospital (i.e. for patients in nursing homes or their own homes). Wyre PCT also hosts the occupational therapy service for Lancashire County Council locally. Adding even further organisational complexity, the dieticians that provide the core dietetics service to people living in the community are hosted by Chorley and South Ribble PCT near Preston. Finally, clinical psychologists are separately employed by another organisation altogether, Lancashire Care Trust, which is again based near Preston (note: at the time of our fieldwork, however, there were no clinical psychologists working in the Blackpool, Fylde and Wyre areas).

Lancashire County Council provides social services from separate district team bases in the Fylde and Wyre areas. Social workers commission the range of home care, meals-on-wheels, rehabilitation services and residential and day care with the aim of enabling people to retain their independence. At the start of the fieldwork, the situation was that all adult services (age 18–death) were commissioned and provided on an individual district basis. Following the April 2004 restructuring older people's services have been separated out from services for younger adults with physical disabilities, etc., and each of those is now managed for Fylde and Wyre as a whole. What this means for stroke is that depending on the service user's age they will either be dealt with as part of the older people's services or as part of the adult services.

At Blackpool Victoria Hospital, for example, social workers from Fylde and Wyre are part of an Integrated Hospital Discharge Team (co-located with health staff and social workers from Blackpool Social Services) that was established in 2002. They deal with the relatively limited number of stroke patients going straight from acute hospital care into nursing or residential care or back home with support (handing cases onto a community-based social worker, or back to the service user's existing social worker if they are already known to social services, and if longer-term input is necessary). Members of the team (whether nurses or social workers, whether employed by Blackpool, or Lancashire) commission all aspects of health and social care services across the entire Blackpool, Fylde and Wyre area in the context of intermediate and continuing care arrangements – that is, they work across professions and employer organisations to access services within the system as a whole depending on where the patient lives and their needs. In doing this, the team has access to the IT systems (containing patient and service user information) of all three partner organisations: Blackpool, Fylde and Wyre Hospitals NHS Trust, Blackpool Social Services and Lancashire Social Services (Fylde and Wyre Districts).

By contrast, there are no social workers attached to Blackpool, Fylde and Wyre NHS Trust's community rehabilitation hospitals (Clifton, Rossall, Wesham and Bispham, etc.). Here, nursing staff refer patients ready for



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discharge directly to the relevant community social work team in either Blackpool, Fylde or Wyre (for commissioning of individual packages of care and subsequent care management). It was an issue of concern raised by all health staff interviewees (managers and professionals) that, since attached social workers were removed from the community hospitals in 2002, they now have to deal with 30–40 different social workers for patients on their ward. From the social services perspective, however, this approach is better because it prevents the hospital social workers being 'isolated'. It also means that, rather than dealing with patients by type of client group (i.e. hospital patients), social workers are concentrating more on what one interviewee referred to as the 'service user as an individual "whole person"' if they follow them through their whole care pathway from community to hospital and back again.

In addition to general social services provision, intermediate care (consisting of social work, occupational therapy, physiotherapy and district nurse input; domiciliary services provided by Leonard Cheshire; and residential beds, six for Fylde at the Millbank home and seven for Wyre at the ex-local-authority home Thornton House) is available to help older people (including stroke patients) bridge the gap between leaving hospital and returning home. At the start of the fieldwork intermediate care was commissioned and provided by separate teams for each district, but in September 2004, following a review prompted by the fact that initial Performance Fund monies used by social services to fund the service were coming to an end, Lancashire Social Services and Fylde and Wyre PCTs established an integrated intermediate-care service across the whole area. Blackpool unitary authority has its own arrangements for intermediate care including, for example, the facility known as the ARC (which provides both care-home and domiciliary support). Lancashire County Council also provides a Welfare Rights Service from bases in Preston (for Fylde) and Lancaster (for Wyre). Service users are referred there by the Fylde and Wyre social workers as appropriate. Service users taking on Direct Payments are also referred to independent user-advocacy organisations, such as the Rowan Organisation, for advice regarding advertising for, interviewing and employing carers, setting up a bank account and so on.

In partnership with the district council housing authorities in Fylde and Wyre and private- and voluntary-sector organisations, social services also provide care and support to older people living in sheltered housing accommodation who are not able to live at home but who do not need high levels of 24-hour care provided by residential or nursing homes. Extra care sheltered housing is also provided to offer people who might otherwise consider residential care the chance to stay independent but with greater levels of support and rehabilitation and domiciliary-care packages tailored to suit their individual needs. In relation to supported housing, there is acknowledgement of a general lack of provision in the Blackpool, Fylde and Wyre area. However, social services in Fylde and Wyre have a number of 'extra care housing schemes now that are coming on line' specifically in the context of intermediate care. Lastly, home adaptations are also carried out for patients who return to their own homes following discharge by various different private firms and voluntary organisations under contract to social services.

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By comparison with South Tyneside in particular there are within this part of Lancashire a large number of partnerships that operate at different levels relevant to the stroke agenda. These groups serve to add to organisational complexity around stroke locally because they do not all clearly relate to each other, but have different constituencies, and operate to different agendas. Such partnerships include, at the highest level, the NSF for Older People LIT, which is chaired by the Chief Executive of one of the local PCTs and attended by LIT sub-group chairs (there are sub-groups for stroke, intermediate-care and other service areas), acute and community hospital managers, mental health, the Ambulance Service, social services and the Stroke Association. The LIT also has a stroke sub-group known as the Standard 5 Local Implementation Group (LIG), which is chaired by the stroke consultant and attended by acute and community hospital managers, the stroke specialist nurse, nurse managers and allied health professionals, representatives from the acute hospital, a GP who is also a local PCT Professional Executive Committee Chair, PCT commissioning managers, etc. It is the responsibility of the Standard 5 LIG to co-ordinate development of the local Stroke Plan.

Other organisational partnerships include, at the level of commissioning, the joint commissioning arrangements between Blackpool, Fylde and Wyre PCTs (social services has a seat on the Joint Commissioning Board); and, at the operational level, Integrated Teams for Discharge from Blackpool Victoria and intermediate care. Among the different professional groups there are partnership mechanisms including a Clinical Leaders Forum, which aims to foster joint working across primary and secondary care and includes Clinical Directors from Blackpool Victoria Hospital, Professional Executive Committee chairs from the three local PCTs and other senior GPs (one of the issues this group was planning to look at is TIA and stroke management); and a forum organised by Wyre PCT, where all allied health professionals can meet irrespective of which organisation employs them (the group had met twice by the time of fieldwork in early 2004). Finally, from a social service perspective there were plans in 2004 to appoint a health co-ordinator, part of whose job would be to liaise with NHS organisations and attend meetings such as the Standard 5 LIG.

Such mechanisms, although they had been relatively slow to get off the ground in terms of inclusive membership across the health system (e.g. primary care as well as acute) were felt to be leading to greater understanding and potential joint developments to improve services in future:

*I think that's [Standard 5 LIG] been very useful. Because I think [acute hospital] had got to the point where it knew what was happening or not happening in our services – knew what was blocked in terms of what we wanted to develop at the community hospital – but didn't know the primary-care picture. So it's been quite useful to use those meetings [which include a GP representative] to catch up and develop things.*

From a social services perspective, however:

*We [specifically the intermediate-care co-ordinator] did attend ... a couple of the stroke [Standard 5 LIG] meetings originally because I think she was asked to contribute to a care pathway that was drawn up. It was drawn up by health and then sent to us for comment. It was quite interesting their perception of where they thought we should be involved – at the end to deal with benefits. Well we haven't done benefits for years...somebody else does that, it's their role not social services'. So it was quite interesting to see how we were viewed*

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*[i.e. very much as the 'add-on' at the end of NHS provision, not as a full partner in the process of developing the overall stroke pathway]... But again, that's communication isn't it?*

Once again, one of the main factors affecting speed of progress in terms of service developments locally – either within Blackpool, Fylde and Wyre Hospitals Trust or through partnerships with the PCTs and social services – was the level of organisational turbulence in the local health and social care system in recent years. This meant, for example, that the relevant organisations were again questioning whether they had the right membership of the NSF for Older People LIT at the time of fieldwork in early 2004. At the same time Lancashire Social Services were also restructuring their older people's and adult physical disabilities services (as described above) to coincide with PCT arrangements. Despite the potential improvement that this should bring in future it meant that 'the PCTs have all new senior staff to liaise with'. In addition, Blackpool, Fylde and Wyre Hospitals Trust is itself a recent merger of the Acute and Community Trusts (which had involved a change of employer to Wyre PCT for the majority of therapists and dieticians working locally); and there were, it was said, very different professional and organisational cultures that now needed addressing. As interviewees argued, from the different perspectives of, respectively, the acute and community hospitals:

*We hadn't previously had very motivated managers in the community hospitals...it's always been difficult to drive anything out there [but] we have got the wherewithal now [that the acute and community hospitals are under one Directorate and new managerial resources have been appointed] between us to do things.*

*We complain about Victoria Hospital [e.g. over bed management]... I can see the problems they have to some degree, but I don't think there is always an understanding. They say the same about us I'm sure. There is a lack of communication, it is more fractured than it ought to be... But the power base is now there and not here so we are the losers as far as I'm concerned.*

The merger of Acute and Community Trusts also meant the 'the stroke group [Standard 5 LIG] fell apart' and had to be reconstituted and re-energised with considerable effort.

Another cited example of the effects of organisational turbulence and complexity on the effectiveness of partnerships related to commissioning by PCTs:

*Although there are three PCTs, they have one, Blackpool PCT have a commissioning team that represents Blackpool, Wyre and Fylde. So in terms of our discussion or negotiation it should really be through that one PCT for the development of services. Having said that I understand that they might be about to change that...which will make it very difficult because it will mean that we have to negotiate with all three... It makes things harder.*

A specific illustration of such difficulties in relation to stroke services was around commissioning priorities for speech and language therapy services. As the host organisation employing allied health professionals locally, Wyre PCT had agreed to fund it's third of an additional SALT (supported by Blackpool, Fylde and Wyre Hospitals Trust) from 2004. However, Blackpool and Fylde PCTs did not regard this post as a commissioning priority. As it was not viable to have a post just for the Wyre PCT area it did not proceed, and there remains a shortage of speech and language therapy services, as described

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elsewhere in this report. Part of the explanation is that joint commissioning arrangements do not cover all aspects of services. For example, the joint commissioning forum that existed until early 2004 did cover equipment, but therapy provision was a local commissioning issue (i.e. dealt with by the three PCTs separately on the basis of their individual population needs). Another illustration of developments being slowed by having separate PCT priorities is that of intermediate care. Here, one NHS interviewee explained that the strategy was formulated within the relevant LIT sub-group and 'had gone to the LIT and had been approved, but we were told that the three PCTs each wanted to do different things'. Similarly, in relation to continuing care, according to one interviewee:

*they all seem to work independently...they all work differently... With Fylde while the continuing care [panel] process is going on, you cannot move somebody out of a hospital bed. It's not the same for Blackpool, we could actually move somebody into say a private nursing home and the continuing-care process would carry on while they were in that private nursing home. So that makes a few difficulties.*

Finally, it is important to note, once again, the effects of the particular geography of the acute health system across Lancashire as a region, which some local interviewees thought impacted on resources for developing stroke services (e.g. provision of allied health professionals):

*The emphasis in this area, and I don't have a worry with this, is not neuro. The emphasis is cardiovascular. So you know the priority [for funding] tends to go there... Our neuro really is Preston... So that might be where some of the problems come from, ...the prioritisation higher up.*

There was also a view that funding for stroke generally tends to emphasise the acute sector, and that this misses the opportunities that PCTs could develop around prevention (e.g. diet, exercise advice, etc). As another interviewee summed up: 'The point I'm making is that it's hard to sort of standardise...it's such a big area. So everything is sort of fighting against each other at the moment really'.

### **4.2.5 Central–local relationships: stroke as a priority**

We have in this section referred to the widespread view across the study sites that historically there has been some under-funding of stroke services. This is important in terms of continuity of care because of the direct effect of any limited funding upon levels of staffing at an operational level. In this respect in Darlington the Darzi report in general and the subsequent Stroke Services Plan in particular highlight the scale of investment required to develop a well-staffed specialist stroke service. Part of the problem, it was widely suggested, is the setting of national priorities, and, thereafter, of local priorities.

The NSF for Older People was said by one interviewee in South Tyneside to 'give us focus: it's given us structure and it's given us targets to work to'. The same interviewee also remarked, however, that 'we haven't been as lucky as some of the other NSFs that have come with funding'. Other NSFs also, in her view, had clearer targets than the NSF for Older People; although within the latter 'what works very well is stroke because it has got hard targets'. According to another interviewee in South Tyneside 'what we do around stroke is by and large driven by the NSF for Older People'. Work was, of course, going on before the NSF was written but it has given it 'a bit more

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focus, a bit more structure'. This same interviewee also underlined the nature of the focus the NSF gave to health and social care managers and professionals alike: 'it's not something that's nice to have and if you have a spare five minutes you might like to have a look at that. It is a case of this is the gospel according to and this is what you will adhere to'. Interestingly, of all the reservations or criticisms of NSF voiced across the fieldwork sites none were to do with the firmness with which milestones and targets were set and monitored. More common in the case of the NSF for Older People was the view that the guidance in relation to some standards – though not stroke – was 'too woolly' or imprecise: 'it doesn't clearly state that you need to have acute beds, it says you have to have a specialist service...we have got a specialist rehabilitation service [but] not a total service'.

What was clearly agreed across the three sites was that, as the above interviewee remarked, an NSF milestone is not mere aspiration. Whatever the traffic-light system in place a red light showing slow progress towards meeting a milestone was universally regarded as a prompt for urgent collective action. Both the NSF milestones and to a lesser extent the Sentinel Audit findings provide powerful ammunition for local service development: those working in the stroke services can hold them up to managers 'and say that's where we need the investment'.

Across the three study localities one of the most striking features of our interviews with service professionals – and indeed with some patients and their carers – in the stroke field was the near unanimity that stroke is accorded too little priority nationally. There were several strands to this argument. First, and especially striking, was the rhetorical question posed by one stroke consultant: 'in terms of priorities based on severity of illness what is the difference between a heart attack and a head attack?' This question was memorably answered by another stroke consultant who said that he would prefer two severe heart attacks to one severe head attack (i.e. stroke). In other words, in an argument voiced and expanded by many other specialists – clinicians, nurses and therapists – and service managers: why is coronary heart disease the subject of a separate NSF and the recipient of substantial ring-fenced monies from central government, while stroke is not? This is a question not about national prevalence or mortality rates – or about coronary heart disease (CHD) rightly being a national priority. It is a question about relative prevalence and mortality rates allied in the case of stroke to long-term effects (and associated financial costs to the NHS and local authorities) upon physical and psychological well-being; not only upon patients but upon their families and carers.

As one senior PCT manager in South Tyneside remarked:

*The difficulty with stroke is we have really been carving that money out of fresh air, whereas coronary heart disease has millions, multi-millions across the country; millions [here] invested in CHD, very worthy. So that NSF came with all the money attached and totally ring-fenced.*

A similar view was expressed by an acute trust colleague in this locality. The CHD NSF was the first; and the need to mark not just the priority accorded to CHD nationally but the importance attached to NSF themselves meant that 'we had money pelted at us left, right and centre'. Succeeding NSFs, however, it was ruefully noted, have come with no similar monies attached. In the case of CHD, in South Tyneside the funding had allowed two full-time and two part-

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time community-based specialist nurses to be appointed. Moreover, this is recurrent money – ‘on the back of the CHD NSF’ – therefore each of the nursing posts have substantive contacts.

*Q: And what is the comparable resource for stroke?*

*A: There isn't one...from the specialist knowledge point of view, specialist knowledge out there is around management of patients with cardiology problems, but not stroke.*

In fact there is some clear preventive crossover with registers of people with a family history of premature vascular disease operating to the benefit of those at risk of either CHD or stroke.

Irrespective of the relative national priority attached to stroke and CHD, it was argued in South Tyneside that locally the NSF for older people, together with the Sentinel Audit, had highlighted the need to invest in a stroke service development – especially but not exclusively in providing acute beds. The PCT's LDP 2003–2006 spelt out (with an implicit rank order) the broad national priorities, with access, cancer, CHD, mental health and older people being the first five. Among the stated priorities for older people was the development, by April 2004 (1 year after the LDP's publication), of a specialist stroke service, specifically (Darlington Primary Care Trust, 2003):

- *To develop a stroke ward at South Tyneside General Hospital with input from a medical specialist in stroke, speech and language therapy, specialist nursing and clinical psychology.*
- *To provide rapid access to diagnostic tests.*
- *To develop joint protocols/templates for the management of stroke patients in partnership with GPs... This will include setting up systems to identify 'at risk' patients.*

The accompanying risk assessment candidly warned that ‘if rapid access to specialist advice, support and investigations is not available, there is the potential that older people will face unnecessary disability or death. Medical admissions will increase and more complex packages of care will be required upon discharge’. In South Tyneside the case for investment was undoubtedly enhanced by the subsequent appointment of a specialist stroke consultant. In part this was simply a case of having a clinician who was not only willing to manage dedicated acute stroke beds but saw them as essential to the development of a coherent specialist stroke service.

Across all three sites in the study there was a widespread view among stroke professionals – acknowledged to be understandable given their interests – that all the money, all the interest and all the priority nationally had gone towards CHD. A declared national priority – and one not disputed as such – for which ‘real money followed the stated policy’. Stroke service development, it was argued, has suffered by comparison with that for CHD. One senior clinician was clear about the discrepancy: ‘It's disappointing. The NSF for elderly came with no money.’ Stroke, he said, ‘is the fourth most important cause of death, but it is the first cause of disability. I think they have got the priority wrong. I think stroke is the same as CHD. It shouldn't have been dumped in the elderly NSF. It should have been seen as a vascular problem...it has got no resources and no recognition. It wasn't a good decision. I am afraid they want the NSF on the cheap. It isn't going to be delivered.’ According to another senior clinician: ‘obviously there should have

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been money following the stroke service, stroke is lost in the services for older people. It is and continues to be a relatively Cinderella specialty.'

This was a view shared by a senior acute trust manager who referred to stroke as having suffered 'a little by comparison to cancer and CHD and access'. He also spelt out what several other interviewees made clear were the main priorities: 'The top priority is access, your next priorities are NSF's and your third priority is financial balance'. Thus, he said, whereas the NSF targets were important they 'are not actively performance managed' in the way access and waiting lists have been.

This view from clinicians and service managers was one strongly shared. Asked about the relative priority accorded to CHD and stroke (and associated funding) another senior manager replied:

*Yes, I don't know why. It is true that heart attacks kill more people than stroke, but the debilitating effects of stroke in general are much more pronounced.*

*Q: And costly to the service overall?*

*A: Absolutely; and that is something we need to push at central level. The reality is that CHD has an NSF all of its own. Stroke was buried within older people and its not just an old person's problem.*

*Q: With real consequences for service development at local level?*

*A: Yes.*

The main consequence, it was argued, was continued under-investment in stroke services. Evident in different ways across the three sites, this under-investment was most apparent in the lack of specialist services across the whole patient journey and the shortage of key staff. In the case of Darlington, for example, a succession of reports and plans – Darzi, *Access, Choice and Sustainability* and the South Durham Stroke Services Plan – had spelt out this relative under-investment and, in the case of the Stroke Services Plan, the staffing (and associated funding) required to develop well-established specialist stroke services in both hospital and community.

Several interviewees across the statutory sector in Darlington – senior service managers and service professionals alike – acknowledged such under-investment in stroke services: and also that it was not one of the top priorities within the first year of the LDP process. This was partly a function of new organisations with new staff learning how to operate within a new planning and priorities framework. It was principally a function, however, of two other things. First, what was seen as the more pressing priorities – and nationally determined priorities – of access and waiting times. As one senior health-service manager bluntly remarked in Autumn 2004 'we are still driven by access and waiting times'. No matter what the LDP might say about implementation of the local stroke service plan as a 'key deliverable', there were many other, and many other even more pressing, 'key deliverables'. And second, it was a function of the context of significant organisational turbulence and complexity discussed above.

As 1 April 2004 approached, managers candidly accepted that they were going to miss the NSF for Older People milestone stating that 'a 100% of general hospitals which care for people with a stroke to have a specialised stroke service as described in the stroke service model'. The problem for local service managers was that the milestone refers to general hospitals and not

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to acute trusts; therefore, it was readily conceded, Darlington (Memorial Hospital) should have such a properly constituted stroke service, but – it was equally readily agreed – it didn't have one and wouldn't have by 1 April 2004. Here, however, the authorities locally were constrained by the wider planning and organisational context. The Darzi review was clear in its recommendation that the specialist acute stroke service for South Durham be provided at Bishop Auckland and that Darlington be run down as a consequence. There would inevitably be a transitional period during which Darlington Memorial Hospital continued to provide acute stroke care – that is, prior to the development of a centralised service in Bishop Auckland. In this transitional period Darlington would be effectively running down its acute service – emphatically not in the sense of providing a lower-quality service but in terms of not investing in the development of a specialist service.

So, yes, it was said, it is entirely plausible and reasonable when asked – whether by the Strategic Health Authority, Department of Health or others – to explain that the milestone was not met because it is a marker now, in effect, on the wrong road. But it was simultaneously accepted that having thus triggered a red light – by missing an important NSF target – there was a need collectively for the PCTs and others to, as one manager put it in August 2004, 'recognise that stroke needs to be a priority for this year's [LDP] process and the subsequent 3-year planning cycle. So we have all committed to the fact that once the business case comes out it will receive some level of investment.' The same interviewee said that 'everybody has a clear understanding about how much we are at risk around this particular area...it will gain this year as a result'. It should be said that this was recognition of a dual-faceted risk: the risk associated with not reaching an NSF milestone, but more importantly the risk associated with any continued under-investment in stroke services.

### **4.2.6 Summary**

There are two facets to inter-organisational complexity relevant to the delivery of continuity of care for patients and service users (and for their families and carers). First is the degree of inter-organisational simplicity/difficulty in terms of not only the number of organisations responsible in any one locality for service commissioning and provision, but also the similarities or differences in their size, remit and responsibilities, resource base, history and culture. Second is the level of organisational turbulence associated with major restructuring – notably, in the case of this study, the re-organisation of health services in 2002. All the evidence suggests that successful partnership working and effective service integration are more likely when the context is one of least turbulence and most inter-organisational simplicity (i.e. conterminosity).

The most recent Wanless report noted 'the complexity of partnership working in areas where the number of partner organisations is large due to the lack of coterminosity' (Wanless, 2004). He did not state the converse, but part of our rationale for selecting localities in this study was that they reflect a spectrum of complexity. Thus, whereas South Tyneside has a conterminous PCT, NHS Acute Trust and unitary local authority (i.e. responsible, *inter alia*, for social services and housing), in Darlington the unitary local authority is conterminous with the PCT but relates to an acute trust covering the whole of



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Darlington and County Durham – with Darlington PCT one of six within its boundaries. In Lancashire, because of the complexity of its relationships with health partners (eight PCTs and four acute trusts) and housing partners (11 district councils and Preston City Council) we focused on one locality. Fylde and Wyre Districts in north-west Lancashire were selected to reflect the added complexity that acute stroke services are provided out of county in neighbouring Blackpool.

It is important to stress that conterminosity is no guarantee of successful joined-up working across organisational and professional boundaries – nor does an absence of conterminosity precludes it – but it is, as one interviewee put it, 'a brilliant building block'. It does, however, need to be built upon – to be taken advantage of. This in turn requires a commitment to work in partnership: to avoid organisational self-interest and behave in such a way that locally there are not 'your problems' and 'my problems' but only 'our problems'. This sort of collective commitment to shared aims and objectives, joined-up/partnership working and service integration is inherently easier to generate and develop where there is the simplicity associated with conterminosity rather than the duplication or triplication of partnership arrangements. The latter all too easily mean that the potential discontinuities which exist at any organisational boundary are made worse by different service objectives and different funding priorities. Thus, for example, whereas in South Tyneside joint working around stroke services development is three-way (between local authority, PCT and acute trust) in Darlington it is between the local authority, three South Durham PCTs and an acute trust – newly created in late 2002 – covering six PCTs, two social services authorities and four other district council housing authorities. In Lancashire (Fylde and Wyre) the arrangements are even more complex.

Compounding this inter-organisational complexity there was widespread agreement across the three authorities about the severity of the organisational turbulence surrounding health-service re-organisation in 2002 – which coincided with parallel internal restructuring within local authorities – and the deleterious effects upon partnership working, and the delivery of integration service and continuity of care to individual service recipients. Problems cited included the fragmentation of organisational and professional networks, the loss of senior staff (and with it of 'organisational memory'), and planning blight. The latter was said to have lasted, either side of re-organisation on 1 April 2002, for between 15 and 18 months. In the case of Darlington there was an even longer period of turbulence as stroke service developments were caught up in the wider review of acute services by Professor Darzi and the subsequent adoption of his recommendation to merge existing trusts to create a single, county-wide acute trust.

At the operational level the effects of such inter-organisational complexity are often evident in service developments – for example, increases in staffing – being delayed or dropped as staff cope with uncertainty, with new organisational structures and with building, or re-building, partnership arrangements with new partners. Hence the quotes from interviewees about 'mayhem'; about stroke service planning which 'dropped into a bit of a black hole'; about how such major change 'slows you down'; and that, as one senior NHS Acute Trust manager said:

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*everything you read about mergers, integration, re-organisation [is that] they put organisations back. That's what happened here...everybody has got to start and work together: that takes months, years even.*

There was a general consensus about the importance of one other important aspect of the context within which joined-up, integrated stroke service planning and delivery is expected at local level. This is the priority accorded to stroke services nationally. A priority, it was argued, that – when compared with CHD – fails to acknowledge its prevalence, its profound long-term disabling effects for many people and the scale of associated long-term costs to both health and social services. The comparison with CHD was cited partly to underline the difference between CHD being the subject of a single NSF and stroke being 'buried' within an NSF for Older People. (The latter being all the odder, it was frequently said, given the prevalence of strokes among young people.) In highlighting this difference interviewees were also emphasising the considerable differences in national funding for CHD and stroke. One important result of the considerable investment in CHD services was significant increases in staffing locally. One important effect of an equivalent investment in stroke services, it was argued, would be to improve continuity of care for patients who currently, for example, have virtually no access to clinical psychologists and extremely limited access (especially in the community) to the range of allied health professionals.

Notwithstanding this seriously questioned national ordering of priorities and funding, it was widely conceded that locally stroke services had for too long been too low a priority – with consequent under-funding. Here, too, it has to be said, many interviewees across the study localities emphasised the increasing extent to which they regard local service developments as being determined by the main national priorities (notably access and waiting times) and by the attendant performance management of these priorities.

### **4.3 Professional complexity and continuity of care**

#### **4.3.1 Introduction**

As all the guidance makes clear and as the following sections of this report underline – from the perspectives of patients (and their carers) as well as of service professionals and managers – there are two vital components of a well-developed stroke service. First, that it is an integrated and specialist service across the whole patient journey; that is, primary, secondary (acute), community and domiciliary settings. Second, that the service comprise specialist teams properly constituted in terms not just of the range of professionals involved but their number relative to local rates of incidence. This is a question of sufficient capacity in terms of both numbers of staff involved and the extent to which they are a full-time and a dedicated resource working solely on stroke services. The other vital aspect of such a service, especially when operating at and across organisational and professional boundaries – notably, in the case of this study, around hospital discharge – is team ethos (or culture) and working arrangements. The question here is whether at a minimum the team operates as a multi-disciplinary unit and, ideally, as an inter-disciplinary unit. In other words, in the language of this

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study, whether joined-up working consists of professional groups working together not as separate professionals but as a unified whole. Two tangible markers of how teams work are formal meetings (weekly MDTs and others) and record keeping and sharing. The intangible expressions of team working which we have sought to identify in this study are captured in two ways: first, by observation of team working (in MDTs and other formal meetings) and informally on the ward; and second, by interviews with staff and with patients and carers.

### **4.3.2 Stroke teams: composition and scope**

The guidelines on the most appropriate composition of a specialist stroke team are clear not just in England but elsewhere. For example, the European Stroke Initiative (see [www.eusi-stroke.org/l3\\_pdf/EUSI2003\\_Cerebrovasc\\_Dis.pdf](http://www.eusi-stroke.org/l3_pdf/EUSI2003_Cerebrovasc_Dis.pdf)) recommendations refer to the core disciplines of a specialist stroke team, including medical, nursing, physiotherapy, occupational therapy, speech and language therapy and social work; interestingly, therefore, not including clinical psychology or dietetics. This directly echoes the SIGN recommendations that 'the core MDT should consist of appropriate levels of nursing, medical, physiotherapy, occupational therapy, speech and language therapy and social work staff' (Scottish Intercollegiate Guidelines Network, 2002). The SIGN guidelines spell out that 'the social worker is a member of the multi-disciplinary team delivering care to stroke patients [and] should have a key role in the discharge planning process' (ibid, p.28). By contrast, other disciplines regularly involved in the management of stroke patients – including clinical psychologists and dieticians – should be accessible to the stroke team but not be core members of it (ibid, pp.7, 29). This in turn echoes the Scottish Royal College of Physicians consensus conference on stroke treatment and service delivery (in 2000) that 'good discharge planning will involve full cooperation of primary health care and local social services. Uncoordinated discharge is unacceptable' (Royal College of Physicians of Edinburgh, 2000, p.2). Interestingly, the draft clinical standards for stroke services produced by NHS Quality Improvement Scotland (in March 2003) refers to stroke units including a multi-disciplinary team 'consisting of health care staff' with the 'core membership' comprising 'medical, nursing, occupational therapy, physiotherapy and speech and language therapy', but not social work; although it is essential that there is 'an agreed protocol in place for accessing social work services'.

In England the Royal College's guidelines are in accord with their European and SIGN colleagues: that specialist stroke units are at the core of specialist stroke services and that these units should be staffed by multi-disciplinary teams comprising a core set of disciplines: medical, nursing, therapy (occupational therapy, physiotherapy, speech and language therapy) and social work. However, several interviewees across the three study localities referred to the vagueness of official guidance – the NSF for Older People included – about what in total constitutes a 'specialist stroke service'. There were two alleged areas of imprecision: first, does the specialist hospital stroke unit comprise a single unit combining acute and rehabilitation beds or can it comprise one or the other type of bed, or both types of bed but in physically distinct units? Second, does the specialist service extend either side of

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hospital-based treatment and therapy to include (a) beforehand, primary-care-based preventive services and TIA clinics on the boundary of primary and secondary care and (b) post-hospital-community-based teams providing continuing therapy and secondary prevention – the latter in conjunction with primary-care- and hospital-based review clinics. Certainly the Sentinel Audits asked the question about whether localities have specialist Community Stroke Teams. Successive audits have shown that such teams exist only in a minority of localities. In this study there was a Community Stroke Team in only one of the three localities – South Tyneside. Unlike hospital-based stroke units – comprising acute or rehabilitation beds or both – the Sentinel Audit does not query the composition of such teams.

In October 2003 the Scottish Executive published a CHD and Stroke Strategy which built on the previous Acute Services Review (published in 1998). At the heart of the strategy – and the prior review – is the proposal to establish managed clinical networks which are described in NHS-specific terms: that is, comprising ‘clinicians from all backgrounds and sectors in the NHS in a given clinical area, working across the boundaries between the professions and between primary and secondary care’ (Scottish Executive, 2003, para 25). In relation to stroke the strategy document makes clear the importance not only of ensuring immediate stroke unit care in all hospitals – comprising acute care and rehabilitation – but of providing ‘organised and specialised multi-disciplinary stroke rehabilitation in the community’. The latter ‘can significantly reduce patient’s length of hospital stay and offers more choice to patients and their families’ (ibid, para 107). The strategy speaks of it being very important for people who have had a stroke to be monitored ‘for the remainder of their lives’. To this end ‘hospitals, primary care and social services need to jointly develop a strategy to provide the follow-up, support and treatments that are required to maximise the patient’s and family’s quality of life’ (ibid, para 114).

The issue for this study was what constitutes a specialist service in terms of the professional groups (and, therefore, expertise) expected to be part of specialist stroke teams – both hospital-based and community-based. This, of course, is to imply that an integrated specialist stroke service is one which spans hospital and community services even if it is formally comprised of two teams: the inpatient service (whether separate acute and rehabilitation or combined) and the Community Stroke Team.

Throughout the period of this study, none of the three selected localities had such an integrated specialist service spanning hospital-based and community-based services. In South Tyneside there was a hospital-based (16-bed) Stroke Rehabilitation Unit (with a well-resourced team) and a small Community Stroke Team, but no acute beds – although funding for four such beds, as indicated above, was agreed towards the end of our fieldwork. In Darlington there were six Stroke Rehabilitation Beds on a hospital medical ward (with a relatively thinly resourced, and non-specialist, team) but no acute beds and no Community Stroke Team. In Lancashire (Fylde and Wyre) there were 20 acute stroke beds (at Blackpool Victoria Infirmary) and several stroke rehabilitation beds in surrounding community hospitals, but no Community Stroke Team.

In all three localities there were some important common concerns about stroke team composition: first, among general staff shortages, a lack of

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clinical psychology input – although this latter was a concern much less marked in South Tyneside (where there was a significant, 0.5 wte, specialist hospital-based service) than in Darlington and Fylde and Wyre where there was virtually none, in either the hospitals or the community; and second, social work input to the specialist stroke service and wider relationships between health and social care professionals. The latter is of particular interest here in view of our focus upon the hinge point of hospital discharge – precisely the point at and around which these professional groups need to work in partnership to ensure continuity of care across this important point of transfer and transition. We deal with this issue first before looking at the lack of clinical psychology input within the broader context of under-staffing across services as a whole.

### **4.3.3 Social work involvement and health and social care relationships**

In one of the study localities we observed and were told of a disagreement between hospital staff and social services staff about appropriate care and support for people after their stay in hospital. This was an observation made during attendance at MDTs and did not relate to one of the patients recruited to this study. At the heart of the disagreement was a dispute about whether a particular patient should go directly from hospital into long-term care. It was the consensus of the stroke team in the hospital – indeed, unanimously the view of medical, nursing and therapy staff – that although this particular patient had made a significant recovery after a dense stroke it was insufficient to be able to look after herself safely at home: ‘she wouldn’t’, it was said, ‘even be safe in sheltered accommodation’. Although her physical functioning had improved she was unable to wash and dress unaided and was also cognitively impaired to the extent that she was unaware on a kitchen assessment in the unit that she had put the electric kettle on the gas hob. All staff on the stroke unit agreed that even a home visit wasn’t appropriate because the patient was ‘never going to be fit and well enough to go home. We didn’t feel this lady was safe to take out on a home visit, and nor would she be in the future’. After 13 weeks on the Stroke Rehabilitation Unit the unanimous view of staff on the unit – a view shared by the patient’s family – was that for her own safety the patient should go into residential care. This was something discussed at length at MDTs over several weeks – at none of which, however, there was a social worker present. When appraised of this recommendation social service staff insisted that the patient should be assessed on a home visit by a social services occupational therapist with a view to either providing intensive, short-term social services support in her own home or spending a period in intermediate care. The latter was the suggested option; one that was opposed by hospital staff and family alike. Their shared view was that although mobile the patient ‘had no concept of what was going on around her’.

The concern expressed by hospital staff was five-fold. First, that their whole ethos was to do everything possible to enable people to return to their own homes with as much independence as possible. This, it was repeatedly made clear, is the collective aim: we want them to go home if that is their wish and if we’ve done an environmental visit and home visit to ensure that they are able to look after themselves safely – with appropriate support. But if it turns

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out, for whatever reason, that they are not going to be able to go home safely, then we want them to go to the next best and safest place for them: that is, in some cases, into long-term residential care. It is, it was strongly argued, emphatically not the first choice, but it may in the end be the best choice. The second concern was that despite this general approach the team's collective professional opinion about the patient's level of attainment, risk and potential were being questioned; and this after 13 weeks' intensive treatment, therapy and care. Third, this judgement was being questioned by staff who had not been present at any MDT meetings – or other meetings – over that 13-week period. Fourth, putting a patient through another assessment of their ability was an unwarranted imposition on the patient with an attendant delay in transfer. Finally that such a delay in turn entailed a prolonged stay, uncertainty for the patient and family and potential discontinuity of two moves – from hospital to long-term care via intermediate care – rather than the one move.

From the perspective of social services staff this case illustrated two important points of principle, as well as one persistent practical problem. The points of principle were first, that no-one should move directly from hospital to long-term residential care, and second, that social services' assessments of risk should be given at least as much weight as those of health colleagues – the latter, it was argued, typically being more risk-averse. There were, it was argued, 'very different perceptions of risk in the community and the social model of disability'. In addition, it was said, there was insufficient understanding of the range of social services support available – including, in this particular case, 24-hour support for short periods to carry out an extended risk assessment; that is, a much fuller assessment than possible on the typical 1-hour home visit from hospital. The persistent practical problem raised was that of resource scarcity and staff capacity, in the light of which – as discussed previously – it wasn't possible to have a dedicated social worker presence on the stroke team. This, it was argued, would be something sought equally by other specialist teams working with other long-term conditions.

In fact the issue of resource pressures upon social services was conceded by hospital staff; although there was some concern expressed about how this was being manifested in almost all decisions about long-term placements. There was a view that in late 2003 – when this issue came to a head – social services were under particular pressure because of the imminent introduction of reimbursement charging. One interviewee remarked: 'whoever is sitting on the panel for residential and nursing care are now wanting the social workers to have a full occupational therapy assessment, including a home visit, whether it's appropriate or not...[possibly] a stay in intermediate care even if it isn't appropriate, to say but at least we have tried. That gives them a better case for a placement with funding for residential care, which will delay the process. It isn't patient-centred and it's purely down to funding'.

In the context of this study, specifying the importance of health and social care relationships and of social workers being core members of stroke teams in particular implicitly recognises several things. First, the importance of someone's home circumstances to their long-term recovery. Second, that for many people once they leave hospital, recovery will be at home over the long-term and will be accompanied by long-term social services support (among a range of other health and social care support). It is also, however, recognising

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that strokes can have a profound effect upon the family and that they too often need social support. Finally, and central to this study, it recognises that hospital discharge is a crucial stage along someone's pathway of care; it marks the transition from hospital to home or to some other non-hospital based accommodation. It is precisely because of the significance of this handover at the point of discharge that social work membership of stroke teams – or, rather, non-membership – was an issue in all three of the study localities.

In South Tyneside it was described as 'the glitch in the chain. We don't have one social worker. We have numerous social workers now so they never come to the meeting'. Asked what difference it made not having a social worker as part of the stroke team one team member said 'it makes it harder'. Previously there had been a social worker who also covered two medical wards, but she always attended the Stroke Rehabilitation Unit MDT meetings and any case conferences. The consensus among Stroke Rehabilitation Unit staff was that, as one said, it 'worked extremely well'. As others said, 'they knew more about the patient because they sat in on the team meetings'; 'it would be lovely to have a social worker here because they are part of that team then...it's something that's missed as part of the team'. Another member of the stroke MDT referred to the logistics of 'dealing with lots of different people; rather than having one key person you're chasing them all'. She echoed the views of other team members that it would be 'a huge benefit to have a named social worker' not only to come to MDT meetings but 'to know the patient. Because they don't know a lot of the background, so we miss out a bit there and it would be nice to have that definitely'. In practice, as the 2004 Sentinel Audit shows, named social workers were attached to MDTs in only two-thirds of hospitals nationally. In South Tyneside there was said to be

*...a lack of continuity because social services are getting involved far too late in the patient's pathway in hospital. The majority of people who come through this unit will have some sort of social care needs after they leave hospital. And they need to know about these people early on so that they can plan ahead, both in terms of their budgets and in terms of what they can offer these people in 6–8 weeks' time when we are anticipating them being discharged. It's not that social services aren't there, it's just that they appear on the scene rather too late; essentially at the time of a home visit or just before when we've identified what we think they need and then we are saying 'can you take this on?' and maybe they can or maybe they can't. So that's a major issue...I would like them to be involved much earlier to provide a continuous service.*

According to a fellow team member, there were times when social workers were unable to attend case conferences because of time constraints. Here patients and their families were 'missing out a bit': such occasions, on which families want to be clear about future social support options, are 'better with the presence of a social worker'. Finally, according to one other team member 'I find that you think why aren't they here? You need the continuity of someone who has sat through, learnt how they have done each week and what we have said; and what was said about home and what the home visit was like and everything'. There was, it was argued, a much truer sense of handover (and attendant continuity) when someone had seen over a period of weeks how a patient had developed, what their goals were and how far they had been met.

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South Tyneside Social Care and Health Directorate had decided in principle to withdraw all hospital-based social work and to work instead on an in-reach model. The intention was to concentrate the resources (the six social workers involved) in two general teams, one focusing on intermediate-care and short-term interventions in the community, the other dealing with hospital discharge. It was accepted, however, that in some cases – stroke among them – there was an argument for having a linked social worker (see below): this would be 'linked' or 'lead' rather than 'dedicated' partly because there was such a limited resource – a limit, it should be stressed, readily acknowledged by NHS colleagues – and partly to avoid the perceived former inflexibility of individual social workers being a dedicated resource (whether attached specifically to the stroke service or some other service).

In the case of Lancashire one of the key issues in terms of social services staffing highlighted by health-service staff was the lack of social work co-ordination at the community hospitals. The plan at the time of fieldwork was that

*The Discharge Team [at Blackpool Victoria] is going to look at a link person at that meeting [i.e. attending ward MDT meetings] and then they will then feedback to the social worker, or feedback from the social worker. So we have recognised that there is a problem in not attending, but equally it is not an effective use of social work time at the moment to be going to various hospitals.*

In addition, Lancashire Social Services was planning to put additional, non-qualified staff into the Integrated Hospital Discharge Team during 2004, with the proviso that they would then be better resourced to support the community-based social services team. From a social services perspective, the hope was that the discharge team, which was set up when Blackpool Victoria was a single Acute Trust, would begin to move out into the community hospitals as the merger between the acute and community hospitals into a single trust bedded down.

For the small minority of patients for whom it would be appropriate to discharge straight home from the acute ward at Blackpool Victoria, planning is done at weekly MDT meetings (involving consultants and senior house officers, stroke specialist nurse, ward 20 nursing staff and therapists). Stroke patients on other Blackpool Victoria wards reportedly did not get this level of MDT planning specific to their needs. Discharge is then handled by the discharge team, which liaises closely with district nurses and arranges packages of care under intermediate care, continuing care or social services' domiciliary-care arrangements. However, this team does not have a major role in relation to stroke patients because the majority are transferred to the community hospitals for rehabilitation. For patients discharged from Blackpool Victoria there were at times delays associated with the lack of occupational therapists available to carry out home assessments for patients well enough to go home with domiciliary intermediate-care and/or general social services support.

The Integrated Hospital Discharge Team does not have a role in relation to discharge from the community hospitals. In the latter, nursing staff contact the relevant area team for social services (Fylde or Wyre for Lancashire residents, or Blackpool itself) and patients are then assigned a named social worker on an individual basis. The social worker then contacts the patient and visits them on the ward in order to carry out home-support assessments and



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arrange for their discharge either home (e.g. with a home-care package, home adaptations and equipment provided) or to intermediate care. Unlike previous arrangements in which the community hospitals had their own attached social workers, NHS staff said that having to contact numerous different social workers regarding patients on a single ward was inefficient and made co-ordination of care difficult. Social services took the view that it allows social workers to concentrate on patients' individual needs. They also commented that social workers often 'ring and ring and ring [the community hospitals] and you don't seem to speak to the same nurse twice, and when you do speak to somebody they don't know what's happening'.

Social workers do attend MDT meetings at the various community hospitals but only where it is considered appropriate and necessary – it depends on the patient (such as where care arrangements are highly complex, or where there are disagreements about proposed care) and the ward. This, it was said, is to avoid attending meetings where (now that social workers are not attached to the community hospitals but have a much wider caseload) their attendance is relevant to only one or two patients. In the main, from an NHS viewpoint, discharge arrangements work as follows.

*Depending on what equipment they need, the [occupational therapist] will recommend what services they feel they need and the social worker will then set them up a care package. So that's when your delays start arising because that can take some time. I think social workers work at a different rate to everybody else to be quite honest. What we see as working quickly to get somebody out while they are at their optimum and everything is ok, it doesn't always happen and you get relapses with patients they end up being in for weeks and weeks longer waiting for care packages to be put together. Hopefully that will stop now they [social services] are going to be charged for that.*

Significantly, however, one NHS interviewee did admit:

*I guess again, if the team was actually adequately staffed you probably would do more discharge planning meetings than we do. Pressure on time, we make a judgement on who you really need to do that for...we don't always get the decision right. I mean there is a gap, we don't get this right very often I have to say, that move between rehabilitation and active discharge planning. Although you try and avoid dropping it on the patient and the relative, it doesn't work as well as it should.*

One of the issues to emerge in the context of discharge from the NHS is whether or not patients should go to intermediate care before going home. NHS staff interviewees tended to think that this was, in fact, an unnecessary duplication of services and not necessarily positive from the patient viewpoint.

*We have a little bit of hiccups...because we might agree as a team without social services, with the patient even, on what we think is the most suitable for them, and then they [social services] come and say 'No, I think you should go to intermediate care'. And regardless of the reports that we have written, that's the decision... We have had an example recently of somebody who wanted just to go home... In the end they were sent through intermediate care and at the end of the day in our minds that's going to be two moves rather than just one because the end result is going to be the same...he is not going to progress any further and I think he actually realises that.*

*Just occasionally when we have got somebody ready, close for discharge, rather than take them straight home, they [social services] will say take them to one of the [intermediate care] units. But you see that doesn't seem to make a lot*

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*of sense, because I think in the few cases where they have taken someone for further rehab, the reality is they have done all the rehab they were going to, what's the point of putting them in another rehab... It seems like a waste of money. You know you are asking one lot of people to do one thing and you are asking another lot to do exactly the same thing, what's the point?*

From a social services perspective many of these problems are down to communication and the 'cultural' differences between the two sectors in terms of what it is they are trying to achieve with patients/service users. As one interviewee put it: 'We don't talk the same language and I think we have to remember that sometimes'. More specifically, social services interviewees felt that intermediate care was a potentially important resource – particularly given the relatively long lengths of NHS stays locally – because:

*I firmly believe that hospitals disable people, make people dependent. You are lucky if you get dressed, you don't do your own medication, and if you want a cup of tea you have got to wait until the nurse brings the drink round... You go into a residential rehab unit that's a social care model and you do manage your own medication, you do make your own cup of tea if you are able to, and if you are not able to then we look for ways around that... I accept there is a place for both. I do think that people, particularly with strokes, you initially need the hospital rehabilitation models. But I am not always sure that when the [NHS] team has decided they are fit for discharge and that discharge has to be to a nursing or residential home; I sometimes think they are worth another look.*

### 4.3.4 Community services

As indicated above, there are no clear guidelines on the composition of Community Stroke Teams although there is clear guidance from the Stroke Association about the need for a specialist community service. As the most recent Sentinel Audit in 2004 found, only a quarter of hospitals in England have any form of specialist community stroke service and only 14% have Early Supported Discharge Teams. These low percentages were reflected in this study, where, as indicated above, there were Early Supported Discharge Teams in none and a specialist Community Stroke Team in only one of the three localities – South Tyneside. Here, two features of the team were said to have important effects upon continuity of care for patients – its size and its location. The issue of size was straightforwardly an issue of the small number of staff in the team – one physiotherapist and a 0.6-wte occupational therapist (less than 1.0 wte due to the inability to recruit a full-time occupational therapist) plus one full-time technical instructor: that is, no nursing, speech and language therapy, clinical psychology or social work input. The team takes most of its referrals (approximately 60%) from the Stroke Rehabilitation Unit, with the remainder from GPs, other medical wards and clinics. Being 'pretty thinly spread', members of the team see ex-patients typically for only 6 weeks after discharge. This can, however, be extended if the person is still making improvements towards functional goals – and if the team is otherwise relatively quiet. Visits usually are made – whether by the occupational therapist or physiotherapist – three or four times a week (typically for 40–45 min), but this can be five times a week. Over the period of this study the small size of the team was acknowledged as problematic and repeated bids were made to secure funding for additional posts.

Interestingly, one interviewee remarked that despite its limited capacity (associated with its small size) the Community Stroke Team had had the

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effect of increasing the workload on the Stroke Rehabilitation Unit. Thus, precisely because the Community Stroke Team successfully enabled patients to leave the unit quicker – because they could have follow-up therapy at home – the unit was receiving patients earlier in their treatment, 'so the workload has become heavier for the nurses'. As another interviewee similarly remarked 'what's happened is the caseload has changed. With the Community Stroke Team in post the "walking wounded" are going home sooner. So we seem to be getting heavier patients, which obviously will impact on our lengths of stay'.

After lengthy discussion, South Tyneside Council agreed in 2004 (as indicated above) to fund social work posts to work with community teams: not just for stroke but other long-term conditions (and for palliative care). The old system (pre-2002) had comprised ward-based social workers (see above). This was regarded as unduly inflexible – for example, when staff were sick or on leave – and was therefore changed to create a central resource and point of referral. This latter system in its turn, however, was acknowledged to have been at some cost to links with the wards. A further review in 2004 led to the decision to re-establish a relationship with some wards by appointing linked social workers. The intention was that referrals would still be made to a central point, but that a designated social worker, as ward link, could pick up some of the those referrals immediately. At the end of our fieldwork in autumn 2004 no final decision had been made about whether in the case of the Community Stroke Team this linked social worker would be a full-time or half-time post, although money had been earmarked for a half-time post. The expectation, however, was that given the number of similar claims upon a limited and severely stretched resource the post would be generic, not dedicated specifically to the Community Stroke Team. In the view of one Acute Trust senior manager 'if we have got that named social worker contact it's quicker, it's speedier access and that person becomes part of the team'. So even if, as conceded, they become involved in other areas of work they are the named social worker for the Stroke Rehabilitation Unit and Community Stroke Team. A slightly different view, voiced by one service professional, was that the social worker would only see the patients as inpatients, after which they would go out to area social work teams if they have long-term needs: 'so, there'll be a handover again and I just think that's not what we're looking for...they'll pick them up on the unit but if they're complex cases they'll still go out to the area teams. This social worker won't be able to stay with them and follow them through for however long they need monitoring'.

It was universally agreed that, as one interviewee remarked, 'we definitely need a bigger Community Stroke Team', to include not just social work input but nursing, speech and language therapy and also clinical psychology. The latter was said to be particularly important because, as one interviewee said, 'one thing we know is that many patients put on an awful lot of weight and start smoking again. They get very depressed, very down and very lonely'. One of the main reasons why they put on weight is 'because they're bored, they're not exercising'. Part of the problem is that 'when they go home it's much harder to cope on their own and they suddenly realise what they can and can't do'. In the view of a senior member of the stroke unit team 'the patient's journey in terms of adapting to a disability often just really starts when the patient goes home'. Purely in terms of priorities being formalised as a written bid for funding, at the end of our fieldwork the business case had

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been made for additional speech and language therapy but not for clinical psychology. Long-term augmentation of the Community Stroke Team to include such specialist professional support would, it was argued, enable the development of an Early Supported Discharge service (see below).

As regards location, the issue in South Tyneside was one of co-locating the Community Stroke Team within the Stroke Rehabilitation Ward at South Tyneside hospital (as it is currently) or of locating it within the community. The firm view of those working in the Stroke Rehabilitation Unit – medical, nursing and therapy staff – was that there were significant advantages in having the Community Stroke Team co-located on the ward. The general view of social services staff was that whereas there were advantages in the team being on the ward, 'for the continuity and the patient such a location was not ideal'. The argument was that 'because it's not within a community resource or a home setting it's very clinical and institutionalised; even though they do everything they can to minimise that it's still a hospital ward. And people [patients] behave very differently on a hospital ward, and staff do as well'. The contrasting view, expressed by ward staff, was that:

*We felt really strongly that we wanted them here [on the Stroke Rehabilitation Unit] because they can see patients before they go home. We can go and discuss things and say 'we've got this patient going home' and if it's an overnight stay say 'could you go in at 11 pm'... I think we would lose that if they weren't here.*

Moreover, according to the same interviewee:

*We've got strong connections with them because they're members of the team: because they're here you have lunch together, you have coffee together, you chat...we've got the service agreements that we all do, business meetings that we all do so I think it's really important they're here.*

According to another interviewee it was the Community Stroke Team's physical proximity which meant that they gelled with the stroke unit staff; because they were, in effect, an extended team – the stroke unit's extended arm out into the community.

One interviewee expressed the view that the stroke care pathway was 'a very strong clinical pathway' which reflected 'good integrated working, very high standards': but, she said, 'there is a feeling that it doesn't reach out into the community'. Moreover, the Community Stroke Team 'which is very small, has never actually been based in the community – even though they go out in to the community and deal with people in the community'. It is important to stress that such a description of a perceived clinical bias was not meant pejoratively. The same interviewee remarked that:

*The perception is that they want to maximise somebody's potential. It does feel a very caring system. It feels very person-centred, and you can actually imagine them saying 'oh we'll just hang on until we've got them to do this and do that'. I think it's a really good strong pathway. The atmosphere and the way people are treated really feel nice.*

The same interviewee argued that the Stroke Rehabilitation Unit's philosophy was based on intensive rehabilitation in hospital: 'there isn't a model of continuing therapy in the community'. There was also thought to be initial reservations or caution about intermediate care 'because in their heads it's hospital and home...that's the message they keep reinforcing'.

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The Stroke Services Plan for South Durham and Darlington was clear in its proposal for investment in specialist stroke services across the patient journey: both in a well resourced acute unit at Bishop Auckland and, crucially, in community services. Whereas the plan recognised the part that the embryonic intermediate-care services across South Durham could play, the clear expectation was for the development of community services with a specialist stroke expertise. This was the source of considerable debate in Darlington especially – but not exclusively – where the new PCT and local authority have jointly agreed to invest heavily in the development of intermediate care. Thus although the PCT agreed in principle with the proposal to develop community services – an agreement expressed in its LDP – the expectation was that this would be done by strengthening and developing existing intermediate-care and other community services ‘rather than spending a lot of money on establishing a new community stroke rehabilitation team’. This was in the context of 72 community auxiliary staff already being employed by the PCT, as a central component of this intermediate-care investment. The intention was to develop an integrated therapeutic community rehabilitation service, ‘one strand of which would be people who have had a stroke [but] it wouldn’t be a service specifically for stroke people’.

The view of some interviewees was that it was inappropriate to see stroke as amenable to generic rehabilitation; that those who have had a severe stroke in particular require specialist rehabilitation with a neurological focus. But as one service manager remarked: ‘we get the PCTs (all of them) saying “well fit this is in with our intermediate-care model”...my feeling is that they don’t understand the needs of stroke patients. They understand the needs of people who need generic rehabilitation [but] they don’t have their own specialist expertise’. One health-service professional remarked that: ‘intermediate-care is not the specialist service the [stroke] plan is written for: the therapy in intermediate care is very different to the therapy of a stroke patient; the specialist skills that you need are very different. So intermediate care can’t just absorb this caseload to provide a specialist service unless the staff has got the skills’. She also voiced the other commonly expressed reservation about extant intermediate-care services being used to provide stroke rehabilitation: this was its age limit. Whether 65 or 55, it was argued, many people who have had a stroke are under 55 – indeed many under 45.

A community rehabilitation service – Disability Options – has existed in Darlington since 1998. The team’s composition was a team co-ordinator (0.5 wte as occupational therapist and 0.5 wte as co-ordinator), another 0.5-wte occupational therapist, a full-time senior 1 physiotherapist, a social services care manager (on secondment, full-time), an information officer from the voluntary sector, a part-time support worker and a part-time administrator. Even at full establishment this was a small resource, but due to a series of staffing problems the team has rarely been at its full complement. Operating an open referral system (including self-referral) the team’s remit encompassed any resident in Darlington with a neurological problem (such as multiple sclerosis or stroke) who is 16 or over. In other words, this was not a specialist stroke service, and in practice the team sees few people with strokes. Nevertheless the team’s physiotherapist regularly attended the stroke programme’s MDT on ward 41 and has done so for several years. In addition she saw people on the wards – whether ward 41 or other medical wards – if

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they were worried about who was going to see them in the community. Patients, it was said, 'put an awful lot of trust' in the people they see and often 'are worried about when they are going to leave'. By seeing people on the wards, being aware of their condition and progress throughout their inpatient stay, Disability Options was thus able to provide exactly the sort of 'handover' from hospital to community which patients and carers regularly spoke of as being a vital part of the discharge process (see Section 4.4). She would be able to discuss patients problems with other MDT members and would receive copies of discharge notes. This handover from hospital to community-based colleagues – both occupational therapist and physiotherapist – was described as 'pretty smooth'. It was a smoothness born not just of mutual professional respect but the sort of trust and understanding which regular contact (at weekly MDTs and elsewhere) helps foster. However, one of the difficulties for the stroke rehabilitation programme staff was that this contact was with one small part of the community services in Darlington – and, as indicated above, a service, like intermediate care, with a general focus (albeit, in this case, general neurological focus) not a specialist stroke focus. The other difficulty was that many discharges were to neighbouring authorities and there was no comparable contacts – certainly in terms of attendance at MDTs – with community-based colleagues in Durham or North Yorkshire.

Part of the problem in developing a localised specialist community stroke service, however, is the relatively small number of people in any one locality who have had a stroke severe enough to require intensive specialist rehabilitation after their acute-phase treatment and initial inpatient therapy – the latter stages together comprising approximately 2–3 weeks. Most localities in South Durham have community hospitals and the expectation was that these would be used as the base for intensive rehabilitation. Without a community hospital Darlington, it was anticipated, would provide such intensive, bed-based, rehabilitation either in the newly developed 15-bed intermediate-care facility at Hundons Lane or in independent-sector nursing homes. It was conceded by some service managers that a more realistic option – given the numbers of those concerned, their geographical dispersal across a number of localities and the cost – might be, as one said, 'to have a specialist team of dedicated health workers who go out'. Even though this would increase travel costs 'the quality is there, the effectiveness is there'.

### **4.3.5 Shortages in stroke services staffing**

It is important to note that in their interviews for this study, as indicated above, any caution or reservations expressed by members of the South Tyneside Stroke Rehabilitation Unit about discharging patients from the unit was associated with perceived short-comings – in terms of under-resourcing – in post-discharge services; in an under-developed and severely stretched Community Stroke Team, in embryonic intermediate-care services which themselves had limited specialist expertise in stroke or, likewise, in generic community rehabilitation services – themselves under-staffed and stretched. The preferred ideal (but yet to be developed) model of those working on the unit was indeed 'hospital to home', but with a difference: that is, hospital to home where the latter is via a properly resourced and staffed specialist Early Supported Discharge Team. In other words, not arguing for lengthy intensive

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rehabilitation within the hospital; but, on the contrary, shortening such rehabilitation subject to further intensive rehabilitation being provided at home. And there was a straightforward dual rationale for this preferred model: first, that rehabilitation is best done (and most successful) precisely in the environment in which, over the long term, people are going to be continuing their recovery and return to optimal independence, and second that the single transfer is in principle preferable to multiple transfers on the grounds of continuity of care. Thus reservations about interim/intermediate stages of transfer were related to absence or under-resourcing and under-development of alternative services (e.g. speech and language therapy, clinical psychology and occupational therapy), not to a fixed preference for hospital rehabilitation for as long as possible. Whereas there is a shortage of such services, there will be times, it was argued, when it is right to keep people in hospital to provide the necessary intensive therapy, of whichever kind.

Several interviewees referred to the effect that the currently under-resourced Community Stroke Team had on the overall services. It was precisely because staff on the stroke unit knew the extent of under-resourcing that they kept people on the unit to help achieve the maximum level of independence. And one member of staff said, being able to transfer patients to an Early Supported Discharge Team would 'be absolutely brilliant': it would 'be much safer for the patients, [with] a lot of continuity'. It would also be much better for staff: 'if you knew there was an Early Supported Discharge Team and a fully working Community Stroke Team you could just roll them out and know they're going to be okay'. Without such support there was a reluctance to discharge patients too soon. One thing that the Community Stroke Team clearly is not is an Early Supported Discharge service. It was readily acknowledged in South Tyneside – where there is a close example in neighbouring North Tyneside – that this would be a desirable service development, though not a currently planned one. But the resource implications in terms of increased staffing (in particular, nursing, occupational therapy, speech and language therapy and clinical psychology) are considerable. With the existing Community Stroke Team, even at its reduced level of staff: 'we have sent people out very early and the Community Stroke Team have been in every day; so we have been able to offer that service, but obviously not as much if we had an early discharge service'. And in the absence of properly supported discharge – for example because of sickness and pressure on the Community Stroke Team – the Stroke Rehabilitation Unit 'sometimes will be wanting to hang on to somebody: we do see that in the team; we tend to dig our heels in a bit and say look this is not going to be safe'.

In the case of speech and language therapy, for example, there is no input to the Community Stroke Team. As a result patients requiring further therapy receive this at Moorlands Day Hospital. But the limited capacity there means that from being seen four times a week on the Stroke Rehabilitation Unit, patients will be seen once a week (or, unusually, twice), typically for 8–10 weeks. Moreover there is usually a 2-week wait after discharge until patients have their first outpatient appointment at the day hospital. This, it was said, 'is quite a big gap in terms of the continuation of service'. It also means that where patients are thought to be at risk (e.g. with swallowing problems) they will be kept in hospital for longer. If there was a speech and

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language therapy input to the Community Stroke Team it would be possible to discharge patients sooner because they could be closely monitored at home. At the time of our fieldwork the community speech and language therapy provision was a 0.3-wte post, but this covered all conditions, not just stroke. The problem has been recognised for some years – as the 2003/2006 LDP notes – but, as one service professional remarked, ‘unfortunately the funding is just not there’.

We have outlined in the preceding sections the limited specialist resources available in Darlington, in the context of wider planned service redesign. In Darlington Memorial Hospital, at the time of our fieldwork, patients admitted with an acute stroke were referred to the lead consultant physician (the consultant with an interest in stroke running the stroke rehabilitation programme on ward 41), but only if he was on call. If he was not on call they would become the patients of other consultant physicians and be passed on only if they were accepted on to the stroke programme. Thus in the acute phase stroke patients were admitted to any of the medical wards according to whichever consultant physician was on call. In the sense that the stroke rehabilitation programme occupied six beds on one of these wards – ward 41 – it was (and is) what was described as a semi-dedicated unit. This was certainly the case within the definition set out in the NSP for Older People (and used in the Sentinel Audits) that a stroke unit comprise, *inter alia*, ‘staff working in a discrete ward which has been designated for stroke patients’. It is very important to stress, however, that semi-dedicated does not mean that people admitted to the programme received no specialist or dedicated treatment, rehabilitation and care, because they did. But they received it from staff only part of whose remit is to work on the stroke programme. The only specialist stroke resource was the stroke specialist nurse, but she was appointed as a 0.5-wte stroke nurse and as a 0.5-wte junior sister on ward 41. In her role as stroke specialist nurse she did see people with strokes on the other medical wards (and in other rehabilitation beds), giving advice to staff and advice and information to patients and relatives. She also regularly visited the medical assessment unit or saw anyone with a suspected stroke or T.I.A.

Inevitably, with space on the stroke rehabilitation programme limited (with only six beds) some candidates for the programme had to remain on other medical wards. When this happened the stroke specialist nurse would see the patient as much as possible; but any physiotherapy or occupational therapy would be provided by the therapists working on the general wards: the physiotherapist and occupational therapist on ward 41 could not act as a peripatetic resource. Each of these therapists worked on a half-time basis, therefore providing therapy to patients on ward 41 only on weekday mornings. In practice, stroke patients on ward 41 received therapy as intensive as those on the more fully staffed (and, of course, bigger) Stroke Rehabilitation Unit at South Tyneside. There was also the same clear expectation that exercises would be continued by patients themselves, and by nursing staff, at other times. But unlike South Tyneside, the nursing staff on ward 41 were nursing other patients on this medical ward.

One of the main themes to emerge in relation to stroke services across the Blackpool, Fylde and Wyre areas was under-resourcing, particularly around staffing. As several interviewees argued, such problems serve to exacerbate



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(and are exacerbated by) the difficulties associated with inter-organisational complexity and geography described above.

The team for care of acute stroke patients on ward 20 at Blackpool Victoria Hospital comprises two consultant physicians (during the fieldwork period there was a change of specialist stroke consultant at the Hospitals Trust: the new appointment is now formally the stroke lead with the former lead consultant now having a special interest in stroke), other clinicians under their supervision, nurses, a stroke specialist nurse (who is additional to the general ward nursing establishment), physiotherapists, a dietician and a speech and language therapist. Patients admitted to medical wards other than ward 20 are also ideally seen by the stroke specialist nurse (but some may not be if wards don't inform her that a stroke patient has been admitted), but typically receive specialist care from one of the stroke consultants only if subsequently transferred to ward 20. Although there is formally no social work member of the stroke team, social work input is available via the Integrated Hospital Discharge Team if required.

Although they were regarded as providing a good service to ward 20, and were regular attendees at MDT meetings, speech and language therapy, occupational therapy and dietetic services at Blackpool Victoria were all considered to be short-staffed at the time of our fieldwork. The physiotherapists, dietician and SALTs also work across Blackpool Victoria Hospital as a whole as well as ward 20 (that is, seeing non-stroke patients on other medical wards in the hospital), although some physiotherapists do specialise in stroke. Notably, there was no designated occupational therapy input (again due to the pressures of providing a service under circumstances of general perceived under-staffing) and no clinical psychologist attached to the acute stroke team. In relation to the latter service it is important to note that the lack of provision for stroke services is the same for other patient groups. At the time of the fieldwork, Lancashire Care Trust – which is responsible for mental health services across the county – was providing no clinical psychology service (to patients generally), either at Blackpool Victoria or any of the community hospitals managed by Blackpool, Fylde and Wyre NHS Trust (see below).

The situation in terms of medical and nursing staff was different at each of the community hospitals. In addition to the acute ward at Blackpool Victoria, the main stroke consultant provides medical cover (supported by a second consultant physician with an interest in stroke) for the specialist stroke/neuro rehabilitation Gloucester Unit at Clifton Hospital. However, stroke patients also go on to other elderly rehabilitation wards (not necessarily designated for a stroke consultant). The main stroke consultant does not cover any of the PFI Hospitals (Rossall, Wesham and Bispham), which have consultants dealing with general elderly care. In terms of nursing staff, all of the community hospital sites and individual wards have their own establishments. The general view, particularly regarding the specialist rehabilitation Gloucester Unit at Clifton, was that the nursing team was under-staffed.

In terms of rehabilitative therapy provision, physiotherapists and occupational therapists operate within separate, profession-specific teams located at the community hospitals. Physiotherapists are divided into three teams covering Blackpool (Bispham Community Hospital), Fylde (Wesham Rehabilitation Unit, Lytham Hospital and Clifton Hospital) and Wyre (Rossall Rehabilitation Unit).

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Occupational therapists are similarly divided across the various community hospitals with an additional team at Blackpool Victoria. The SALTs, on the other hand, work geographically across the Blackpool, Fylde and Wyre area as a whole, thus covering Victoria Hospital or particular community hospitals on different days of the week. Rossall Hospital, for instance, has speech and language therapy cover 3 days per week. Different allied health professionals from the various teams work with either hospital inpatients or patients living in the community. All of the dieticians are based at Blackpool Victoria but go out to the community hospitals (such as Clifton) if requested to see particular patients. At Rossall Hospital, for example, the dietician attends once a week.

Physiotherapy, speech and language therapy, occupational therapy and dietetics were all considered short-staffed at the community hospitals. This was particularly the case at Clifton Hospital, where the better coverage was said to be on the specialist neuro/stroke rehabilitation Gloucester Unit rather than the general elderly rehabilitation wards. Even on the Gloucester Unit, however, physiotherapy and occupational therapy coverage was considered to be in short supply and one manager described 'a specific paucity of therapy staff who are skilled in neuro rehabilitation'. In relation to speech and language therapy, the view was that in the hospitals 'they are up to establishment, but I think the establishment is probably inadequate [although they do provide] a good service for our stroke patients in terms of swallowing assessments and also communication problems'. Similarly, 'dietetics...historically just has not developed as other services have developed. So again, I think it's up to establishment but that is grossly under-established for our clinical needs'. Finally, in relation to clinical psychology there was some frustration about the absence of provision locally (the legacy of mental health services moving to a separate organisation when the Community Trust that formerly employed them merged with the Acute Trust to form the current Blackpool, Fylde and Wyre Hospitals Trust). Hence:

*there is not an establishment for those therapists. And it's not just clinical psychologists, it's neuropsychologists who are in short supply anyway, but we have got no establishment locally... I habitually send off a referral to the clinical psychology service and periodically the head of service writes back and says, 'I cannot process these, please stop sending them' and I continue to send them. And my attitude is, well if I am continually asking you to do something, you should be saying to your powers that be, 'Look there is a need here, can I have some funding and can I establish a service?'*

Thus in relation to clinical psychology the general consensus among nhs managers and professional staff interviewed was: 'If you are over 65 you can just about get one, if you are under 65 you cannot. It's a real problem for the whole region really'. Indeed, as the 2004 Sentinel Audit confirms, it is a problem nationally: 'Clinical psychology services for stroke patients remain rare' (Royal College of Physicians, 2004, p.xi). Certainly there was similar widespread agreement across the three study localities that the paucity of clinical psychology input to stroke services was a significant deficit. Here, again, the Stroke Rehabilitation Unit provision at South Tyneside was the exception. In Darlington there was, it was said, 'no doubt that having clinical psychology would be very useful [but] the investment in clinical psychology here is zero and always has been'. This was only a slight exaggeration: there was a limited resource: one clinical psychologist for one afternoon per week for the whole of the hospital's Department of Medicine. In other words, 'to

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cover asthma, heart disease, diabetes, stroke, everything'. As a consequence, patients with low mood or low motivation who would otherwise be referred to clinical psychology were not referred 'because it's a waste of time'. The effects, both in hospital and at home in the community, were acknowledged to be serious for many patients, with depression commonly leading to impaired rehabilitation – both physical and psychological.

Such under-staffing was partly explained by overall levels of funding, but – importantly for this study – was said to be related to the complex organisational arrangements for the provision of therapy services in Blackpool, Fylde and Wyre. Despite the joint PCT arrangements for physiotherapy, occupational therapy and speech and language therapy provision (with Wyre PCT acting as host on behalf also of Fylde and Blackpool PCTs), *commissioning decisions* about allied health professional staffing are made on the basis of the three PCTs' separate assessments of their population needs. This can mean (as was the case in relation to additional speech and language therapy services referred to above) that additional staffing approved by one PCT is blocked by the others. Moreover, the fact that certain groups of professionals – such as dieticians and clinical psychologists – are hosted by organisations outside the Blackpool, Fylde and Wyre areas altogether (respectively Chorley and South Ribble PCT and Lancashire Care Trust, both based near Preston) was said to add to the difficulties local organisations had in making the case for additional staff. The fact that the 'outside' organisations had other funding priorities meant, for example, that dieticians are currently less available in the Blackpool, Fylde and Wyre areas (hence Wyre PCT was looking to 'bring them back'); and, as already noted, clinical psychologists were unavailable altogether.

It is important to stress that this issue of under-staffing was thought by managers and staff interviewed to be the main underlying source of difficulties with continuity of care in stroke services. It impacts along the patient journey – in hospital and at the point of hospital discharge. It was frequently raised as an issue by patients and families and has implications for the whole service, for example in terms of goal setting and progress towards meeting those goals. As one occupational-therapy interviewee put it:

*... if you haven't got the staff to do the treatment plan there is no point having the goals [because it raises patient expectations]. So it's alright to say, 'Oh yes, we do this'. You have got to be able to say 'You have made it'. How are we going to achieve it and carry it out?*

It also means that the hospital has:

*... patients who are waiting 2 weeks for a home visit with an [occupational therapist]. So we have had great difficulty moving people through the system. So there are people who other things being equal we could arrange their discharge and send them home, but inevitably, there is a 2-week delay built into their discharge.*

In relation to physiotherapy,

*We try and keep continuity, but you know it's basically one physio [per ward within Clifton]...and the locum... But normally we try and keep continuity as far as we can. Sometimes that's only available by the assistant support staff. But it really depends on week to week and resources...if somebody is on holiday then...*

Another interviewee summed up the situation post-discharge as follows:

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*Again, I don't think I've ever known anybody get a community physio... Certainly if it was in the Wyre PCT area they wouldn't get a physio from here [Clifton] to go out to see them. It's only from here, plus an [occupational therapist] would go out and so a home visit, but they wouldn't follow up. Because I know the [occupational therapists], for example, were saying that if they had a patient who had been discharged and the stairlift hadn't arrived or something like that, then the patient still stays on their books until that stairlift arrived. And then once everything that they have recommended was done they just walk away from them and didn't do anything for them again then. And I'm sure that's what the physios would say as well.*

In addition to the difficulties created by under-staffing generally, the geography of Blackpool, Fylde and Wyre makes co-ordination of allied health professional services across the various hospital sites even more difficult. As a physiotherapist put it:

*Basically in this area we are not enough of any one discipline. You could do it (co-ordinate effectively and provide a more intensive service) if you were on one site I think more. But you are looking at travelling up to 15 miles to get from one end of the patch to the other end of the patch – 18 miles I think it is.*

### **4.3.6 Culture and working arrangements within stroke teams**

#### **MDTs and other meetings**

Among team members in South Tyneside the general view was that the team on the Stroke Rehabilitation Unit worked in a genuinely inter-disciplinary and not merely a multi-disciplinary way. This was agreed to be due partly to particular current members and partly to the team's culture and ways of working having been institutionalised sufficiently well to survive the loss of members: 'we have been able to have different people with different characteristics into the team as other people have moved on and the team has remained strong'. Two other factors said to be instrumental in team building were: first, being collectively involved not just with individual patients but in business planning, in NSF monitoring and in service development (including, especially, development of the care pathway); second, that the team had no specialist stroke consultant for 5 years. As one team member remarked: 'we have driven the service forward, I think that makes you stronger as well'. The MDT meetings were widely seen as reflecting the team's inter-disciplinary working: 'a lot of communication is passed within disciplines. It is important because you get an update of where everyone is and any problems and there is a chance to discuss that in a multi-disciplinary way – which you wouldn't get without these meetings'. The MDT, according to another member 'is very strong, it works very well'. This was explained mainly by an absence of preciousness about organisational or professional boundaries, but also by certain members who have been in the unit since it opened and have developed 'a good culture'. This culture is bred by a mixture of stability (continuity) among senior staff and particular individuals instilling an understanding of the need for integration – for all the team members to 'link closely with each other'. In a view of another member of the team:

*I think we do work well as a team. I think we all communicate the same things. We are very close. We don't always agree with things but we also say what we feel and we always discuss things. I think that is one of our strengths. We all*

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*know our own area, but we all appreciate each other's roles and each other's expertise.*

There is little doubt about the benefits to patients and carers. Observation of team members working together both in and outside the MDT showed the continuity of care that comes from close team working. There was never a sense of any member of staff saying to patients (or implying) that 'I'm the physio [or occupational therapist or nurse] and I've done my work with you today and now you've got to go and see the occupational therapist [or speech and language therapist] and she works down there but don't ask me what she'll be doing'. This clear impression was borne out by the patients recruited to this study. Each of them spoke of the way in which staff worked together.

Continuity of care at this level of day-to-day practice is often more obvious by its absence than by its presence. It is also reflected in apparently mundane and taken for granted ways of working. For individual patients its absence will exist – even if often they're barely aware of it – in, for example, having to tell one professional what another has said to them or done with them: and to do so not as a mere reminder or clarification but as if the professionals concerned haven't spoken to each other. One therapist on the Stroke Rehabilitation Unit summarised joint working between professionals as follows:

*I know sometimes you get quite a lot of occupational therapist/physiotherapist friction and 'this is my bit and you do that bit and why are you working with an upper limb that's my bit'. I think we are bigger than that...we can see the benefits of, well if we do overlap we do, but we're happy with that. It's not a threatening thing. We all think if it's for the benefit of the patient then we can go with it. I don't think any of us have issues about or preciousness about being responsible for certain tasks.*

Among patients and carers in South Tyneside it was commonly the view that handover and continuity of care within the Stroke Rehabilitation Unit was good. There was no sense of one professional group working in isolation from another. With rare exceptions there was no impression of, for example, nurses being unaware of the recommendations of the speech and language therapist, dietician, occupational therapist or physiotherapist – or indeed being unaware of the reason for the recommendations. There was no sense either of these therapists (or doctors) ignoring the views of nurses. The consensus among patients and carers was that those working on the unit worked well as a team. This was certainly borne out by repeated observation of the weekly unit MDT meetings. The clear impression from such non-participant observation – fortnightly over a period of 30 weeks – was that the meetings reflected exemplary team working: not least in the way that the continuity of individuals' care was discussed as a shared responsibility between the invariably large number and range of professionals present. The meetings were invariably well attended by the full range of medical, nursing and therapy staff. Discussions at these meetings were characterised by four things. First, the absence of any impression of differential status. Thus although senior medical staff were almost always present (including, following his appointment, the stroke consultant) they did not chair, lead or dominate discussions. (Typically meetings were chaired by the stroke specialist nurse or a ward sister.) Similarly, when – as was frequently the case – trainee staff (whether nurses or therapists) were present, their views on individual patients' progress would be sought and taken account of, the same as for

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other team members. The second principal characteristic was the openness of discussions: a genuine airing and sharing of professional opinions. The third characteristic was the complete absence of rancour. The final characteristic was the thoroughness and holistic nature of discussions and the follow-up from week to week of progress with agreed plans, care programmes and tasks. This sort of 'professional continuity' is undoubtedly aided by the physical proximity possible on a single site: and it is one of the clear benefits of a specialist unit occupying dedicated space and having dedicated specialist staff. In South Tyneside's case this benefit extended to the Community Stroke Team being co-located on the unit.

In Darlington the weekly MDTs were regularly attended by the smaller group of professionals staffing the stroke rehabilitation programme. Usually chaired by the consultant, others regularly attending were the ward nursing staff (including the stroke specialist nurse), the occupational therapist, the physiotherapist, the community physiotherapist (from Disability Options) and, as and when available, the SALT. On no occasion over the period of our observation of MDTs (fortnightly for 7 months) was there attendance by a clinical psychologist. The evidence from observation of these meetings was of genuine inter-disciplinary teamwork with careful, holistic consideration of individual patient's progress. There were often frustrations expressed about the lack of a specialist community stroke resource – notwithstanding the good relationship with Disability Options (which was not a specialist stroke service). There were similar frustrations with the need to liaise with so many social services staff across neighbouring authorities as well as Darlington. Here, however, it should be said that the discharge process was eased in this respect by the highly regarded Hospital Discharge Team, based on the floor above ward 41 at Darlington Memorial Hospital. This is a team jointly staffed by a nurse and a social worker. It was cited as an example of good practice by the Joint Reviews Team in 2002.

In Lancashire practice in terms of MDT meetings is highly variable. All therapists except occupational therapists are involved in weekly MDT meetings to discuss individual patients' prognoses, treatment progress and planned transfers to the community hospitals for rehabilitation (or discharge for the small minority where that is appropriate) on ward 20 at Blackpool Victoria (physiotherapist, SALT and dietician are regular attendees) together with the stroke consultants, stroke specialist nurse and other nursing staff. At Clifton Hospital, therapists are involved in weekly MDT meetings to discuss patients' progress and discharge home on the specialist stroke/neuro rehabilitation Gloucester Unit but not all of the other general rehabilitation wards at Clifton Hospital have formal MDT meetings (and these may or may not coincide with the day when the stroke or other medical consultant is also at the community hospital rather than at Blackpool Victoria). The PFI sites (Rossall, Wesham and Bispham Rehabilitation Units), although managed overall by the same manager as Clifton, each operate their own systems regarding ward meetings and meetings with their consultant.

In terms of review meetings with patients and families, these are held at all of the community hospitals, but again it depends on the individual patients and once again there are different practices depending on the professional group concerned, particular hospital, ward and so on. For example, there may be differences between the Gloucester Unit (which is set up as the more

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intensive rehabilitation facility) and the general older-people's wards at Clifton Hospital. A key way, therefore, in which Clifton patients get updated on their progress is through the medical ward round. There are also differences between the PFI sites in terms of the extent to which patients and families are involved in review meetings or consultant rounds. Specifically in relation to goal planning, one manager's overview was that:

*When they go to Clifton they have got goal-planning meetings with them [patients], so then it's the team that discusses what their goals are. If they go to Rossall, Bispham and Wesham there is no goal planning with the patient. We have got goal planning at the multi-disciplinary team meetings but not with the patient...which is problematic.*

In the absence of consistency in terms of patient and family involvement in reviews, one of the main ways in which continuity can be maintained is through the same consultant seeing a patient through their entire inpatient hospital stay. Again, however, because of the particular organisational and geographical service set-up this does not always happen in Blackpool, Fylde and Wyre. As already noted, if stroke patients are admitted to general medical wards at Blackpool Victoria they may not see a stroke consultant until they are transferred by the stroke specialist nurse to the specialist ward 20. At Clifton Hospital, one of the issues raised by staff interviewees was the fact 'the consultants, we still have named beds'. This means that the stroke consultants do not subsequently see stroke patients at Clifton unless they are placed on the Gloucester Unit, or one of the other named wards, by the Blackpool Victoria bed managers who transfer them. At the PFI sites too, stroke patients are not always seen by a stroke consultant throughout their period of inpatient rehabilitation.

Attendance at meetings and reviews concerning stroke patients is a key mechanism for ensuring continuity and co-ordination of care. It is, therefore, one of the main areas where the impact of under-staffing and capacity issues across a geographically dispersed hospital system becomes clear. It was, for example, simply not possible for the stroke specialist nurse to attend all relevant MDT meetings, a fact that effectively limits her co-ordination role to the acute sector. The capacity argument was equally relevant for other health and social services colleagues – consistently staffing such meetings was considered virtually impossible.

### **Records and information exchange**

It is important to note that in one respect the picture of close inter-disciplinary working in South Tyneside was slightly blurred: this was in the writing, compilation and sharing of records. Despite the fact that the stroke pathway – developed by the range of professionals involved – is based on a single set of notes (multi-disciplinary notes) in South Tyneside separate notes are still kept by individual professional groups. Within individual professional groups, for example physiotherapists, notes will follow patients through the whole process: from general medical wards to Stroke Rehabilitation Units to Community Stroke Team to day hospital. It is thus a continuous physiotherapy record, just as there is similarly a continuous occupational therapy record. There was, it was argued, pros but also real (even if apparently mundane) cons about multi-disciplinary records, with

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significant disadvantages for staff so long as these records remain paper records.

'Because,' as one senior therapist remarked, 'what we tend to do at the end of the day – talking about paper notes here – you can't always access them if somebody else is doing it; and that's your 10-minute slot to write your notes. It can be problematic. But eventually – in however many years' time – when we have electronic records that will be the most sensible approach and then you've got pure multi-disciplinary notes...but we are a long way from that'.

In the meantime, it was emphasised, there was ready access to each other's notes. Nevertheless, trying to get a single, shared multi-disciplinary record was, according to one interviewee, 'a nightmare. When you're trying to see what happened to the patient you can't make sense of it...you've got different disciplines that we write in the medical notes and when you try to find the therapy notes they're hidden away in a cardboard box somewhere'.

A nightmare, maybe, but one of a different order to that experienced among the inter-organisational complexity of Lancashire. As just noted in relation to nursing, there is little face-to-face contact between staff working with stroke patients at the acute and community hospitals (i.e. regarding the transfer of individual stroke patients). As one staff interviewee put it: 'In essence you have two teams, an acute team and a rehabilitation team and no wider community team'. This means that most communication across the health system is via written notes. Each allied health professional group and the nurses on ward 20 at Blackpool Victoria write in the main medical notes, which then travel with the patient to the community hospitals. A key issue here is that 'the nursing staff, medical staff and everybody writes in the case notes here, [which means that] you scan it for relevant information and what you get is things like "slept well"..."died peacefully". It's not robust enough'. In addition, the different professional groups keep their own records, and the arrangements for communication between teams and hospital sites are different for each. Because the physiotherapists operate as separately employed teams at Blackpool Victoria and the community hospitals, they appear to keep separate records in each location (i.e. the notes do not travel with the patient). Nursing notes are also 'restarted' from scratch at the community hospitals (a legacy of the merger between the Acute and Community Trusts). SALT notes, on the other hand, are transferred from Blackpool Victoria to relevant colleagues at the community hospitals. Dieticians are based only at Blackpool Victoria and keep their own case care notes at that location. For all groups there may also be telephone discussions regarding individual patients where necessary.

In this context of communication across a complex local NHS organisational system, it is important to note that moves to develop a single assessment protocol had failed in the past. Similarly, in relation to the development of documentation around a coherent stroke care pathway: 'the problem is that the staff are that sick of trying the care pathway, because they have been doing it for 6 years, that they don't complete the documentation at all. They just put the name on the front and put a signature on, but it's not a continuing document'. Despite these problems, managers and staff interviewees across the board still thought that having tools such as single assessment would make a big difference in terms of continuity (not having to reassess patients a number of times, etc.). It would also generally 'make life



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easier and free up a lot of nursing time'. However, it was also stressed that with so many different hospital sites across Blackpool, Fylde and Wyre, there would need to be significant investment in appropriate information technology to back this up. In addition, it will be important to overcome what one interviewee described as a situation where:

*Unfortunately we have got too much ownership of our own professions. We are still very, we don't like people looking at what we are doing and comparing. I think really that would be my one big criticism that we are still not co-operating enough as the whole picture.*

This is part of the legacy of human-resources difficulties associated with the trust merger noted earlier in the context of organisational turbulence and the coming together of different cultures. It is also worth noting that in another context, that of intermediate care and the Integrated Hospital Discharge Team, there were at the time of fieldwork ongoing 6-month pilots of a single assessment protocol between the NHS and Blackpool and Fylde and Wyre Social Services, from which it may be possible to draw wider lessons for other parts of the NHS system. As one of our social service interviewees said:

*I don't think it will make all the difference no, there is still work to be done. But I think it will start to help. You have got to build up the trust element haven't you...knocking down walls and building bridges and all of that?*

As in the other two localities in this study, in Darlington there was no single, full multi-disciplinary patient record: separate disciplines keep their own full notes with summary versions being entered on a single set of notes. A composite note – nursing, physiotherapy, occupational therapy and speech and language therapy – is compiled at the time of a patient's discharge. Progress towards the creation of a single set of notes was cited as one of the tangible, operational examples of the effects of the planning blight referred to above, associated with a context of considerable organisational turbulence and complexity. In such a context, it was also argued, the chances of agreeing and implementing a common electronic record system were slim. Yet, as suggested elsewhere, it will only be such a system which makes single patient records a practicality for busy staff working across organisational boundaries and geographically separate sites.

We examine the issue of continuity in terms of the patient record separately. It is important here, however, to note one other aspect of continuity of records which was mentioned by several interviewees: this is the issue of discharge letters to GPs.

In the case of Lancashire some service managers and professional staff made two specific points about information in relation to contact following discharge. First, a general point that: 'It is hit and miss. We have to develop systems to bring them back in. I mean at least if we knew where they had gone after they were discharged we could bring them back in. At the moment we don't'. Second, as regards information from the hospital to GPs:

*The quality of the discharge letters to GPs, not just in this area but across the board, it's poor in the extreme. It's a printed proforma with a tick box. What might come in 2 or 3 weeks' time in terms of a typed discharge letter that the consultant would do is something else again. But it's two weeks down the line. It's the discharge information that goes out the door with the patient that we are falling down on.*

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In the most extreme case, of one of the 18 patients recruited to this study, the letter was sent 6 months after the patient had been discharged. In other cases in the same locality letters were sent several weeks after discharge. In these circumstances it is unsurprising that some patients, when interviewed at home after discharge, said they were disappointed to have received no visit (or contact) from their GP. Many simply assumed that this would happen shortly after they got home; and would, in effect, represent another facet of continuity – of being handed over from one professional to another. The simplest way to avoid any disappointment may be for ward staff to tell patients and relatives prior to discharge that although a letter is being sent to their GP they should not expect the GP, as a matter of routine, to contact them. Although, of course, they should contact their GP if they are unwell, or the ward staff if they have any queries or concerns. The latter information was, in fact, invariably given to patients.

### ***The role of the stroke specialist nurse: promoting co-ordination and continuity of care***

The NSF for Older People (Standard 5) refers to the need for a designated co-ordinator within the stroke team, though without explicitly recommending the appointment of a stroke co-ordinator. In each of the three study localities an important part in stroke service provision was played by a stroke specialist nurse, although in each of the sites the role played was different; and undoubtedly part of this difference was associated with the relative organisational complexity of the locality.

In Darlington the post was held on a half-time basis, with the remainder of the post-holder's time being as a junior sister on ward 41 – the medical ward on which the six stroke rehabilitation beds were located. As indicated above, given the constraints upon her time the stroke specialist nurse necessarily played a more limited role than would be possible with a full-time post. She did, however, fulfil the important role of being the stroke specialist resource available to advise stroke patients and staff on the other medical wards. She also played an important co-ordinating role in terms of liaison with the Hospital Discharge Team and, where appropriate, with district nursing services. Essentially, however, given the time constraints, her co-ordinating role was one limited to the acute (inpatient) phase of patients' journeys.

The latter was also the case for the stroke specialist nurse in post in Lancashire – in fact at Blackpool Victoria Hospital – since mid-2003. The role is a potentially vital one for securing continuity of care for stroke patients in Blackpool, Fylde and Wyre. Here too, however, there are real issues of capacity, once again made worse by the size of the service system and by geographical dispersal. This means that in so far as the stroke specialist nurse is *de facto* the stroke co-ordinator, that role is only carried out for a very limited part of the patient journey within the acute hospital. Specifically, the stroke specialist nurse is based on the stroke specialist ward at Blackpool Victoria Hospital. The role is additional to the nursing establishment on ward 20 and is currently focused on tasks such as the following.

- Co-ordination of care for stroke patients, specifically in terms of locating those who have been admitted to wards other than ward 20 and ensuring that, where beds are available, they are subsequently moved.

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- Checking patients' medical case notes to see whether appropriate tests (e.g. bloods) have been done.
- Information provision (verbal and leaflets) to patients and families regarding: what is a stroke; what to expect in terms of prognosis and speed of rehabilitation; CT scans and other care that will be provided in the acute hospital and on transfer to one of the community hospitals; if appropriate, risk factors and lifestyle changes to avoid a further stroke. This ideally involves an initial visit and a review visit nearer discharge/transfer from Blackpool Victoria to the community hospitals or elsewhere.
- Development of a discharge booklet for patients giving information on risk factors, useful contacts such as social services and the Stroke Association (this was being developed in early 2004).
- Attending weekly MDT meetings with professional colleagues (consultants and other doctors, nurses, physiotherapists, SALT and dietician) on ward 20.
- Acting as a member of relevant planning groups such as the Standard 5 LIG and provision of information (e.g. on service provision) to those groups for planning purposes.
- Generally acting as stroke 'champion' – the stroke specialist nurse was 'appointed specifically to raise the profile of stroke and get stroke on the map as it were'.
- Undertaking a nurse practitioner degree so that in future she will be able to take additional outpatients and clinics for TIA, etc., at Blackpool Victoria and/or Clifton Hospital.

As one staff interviewee observed: 'I have been here a long time now and for the last 2 years I have noticed some improvement. And the stroke specialist nurse, tremendous – a huge improvement'. Importantly, however, the role is not as effective as it has the potential to be. This is because the stroke specialist nurse 'is a one woman band. She breaks a leg tomorrow...there is nobody to step into her shoes. The service will be provided but to a lesser standard.' This was a view that was shared by patients' and families' experiences regarding information provision (described below). In addition, due to limited resources not all stroke patients are immediately admitted to ward 20; some must wait on the medical assessment unit and other medical wards until a bed becomes available. Importantly, patients tend to receive less specialist stroke care outside of ward 20 whether from the stroke specialist nurse or other colleagues, and as the stroke specialist nurse explained:

*The problem is that because I am chasing around trying to find the strokes [on the other wards] in effect, I can't get back to review the ones I have seen. When you are outside, say on a surgical ward, you need to go back and make sure everything I said needs doing has been done, but I can't always do that... Now that worries me. Because I have patients who sometimes will come back into clinic and they will say, 'Oh well I've stopped taking my aspirin'... Now if I had seen them before they'd gone home, they know exactly why they are on statin and why they are on aspirin so they don't discontinue... So it's things like that that worry me.*

Another related concern around stroke patients being admitted to non-stroke wards was that although:

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*...we do have a stroke proforma and say 'This is what you need to do from a medical point of view for a stroke patient' and 'this is what you should be looking at in the first 24 or 48 hours', the staff in other areas aren't necessarily knowledgeable enough about stroke to do it. So I will go and see a stroke and they will say have random blood sugar done on admission at A&E...and even though it's high I've gone to see them on the surgical ward 2 days after stroke, it won't have been checked again until I've said: 'Well will you check this patient's blood sugar?' And it's 'Well why?'. And you have to go through all the rhyme and reason why you do certain things for strokes.*

In addition:

*If I don't get to see them or they are on a different ward, they don't get the [therapy] goals discussed really. They will get seen by a physio, but not the neurophysio... And they can have very unrealistic expectations, whereas I will try and break it down.*

At the beginning of our fieldwork it was intended to have a 'D Day' where all stroke patients from other wards would be transferred on to ward 20. However, this was later thought not to be viable. A subsequent plan, under discussion with bed managers later in our fieldwork period, was to make sure that all patients in the acute phase are admitted to ward 20 and others who are a few days or weeks into their treatment would be transferred out to make room. The point of this was that the stroke team would then know where all their patients were – 'we have then got control of the beds'. Until that happens, the co-ordination role between wards within the acute hospital remains a key part of the stroke specialist nurse's role; although it was argued, this prevents her focusing on other important aspects of her role and potential improvements to the service. It was for these reasons that the stroke specialist nurse was hoping to train ward 20 nursing staff 'so that they can assess patients and bring them in'. Similarly, a rolling training programme on stroke was planned to 'cascade the knowledge base behind stroke care' for nurses on the other wards to which patients might be admitted in the absence of an available ward 20 bed. At the time of fieldwork it was planned that this would allow for continued provision of the current service and co-ordination function within the acute hospital in the absence of the stroke specialist nurse (on holiday, sickness, etc.), and free up her time to extend the service into additional, more appropriate – that is, clinical – activities (e.g. TIA clinics).

Another, related problem in terms of securing continuity of care is that the role of the stroke specialist nurse effectively stops at the acute hospital boundary and – as is clear from the amounts of patient and family experiences – this is an important issue. It means that once patients are transferred to the community hospitals and elsewhere they lose that focused level of co-ordination and championing of the interests of stroke patients. Managers and staff also pointed to this lack of a stroke specialist nurse in the community setting, but argued – understandably – that covering such a complex and geographically dispersed local health and social care system as a whole is beyond the capacity of one individual in the stroke co-ordinator role:

*That's [already] a full-time job [co-ordinating patients coming from the other Blackpool Victoria wards to ward 20]. And it is how many sites, rehabilitation, Bispham, Rossall, Wesham, here [Clifton], you know it is not possible... I haven't thought about it much but perhaps what you need is someone based in the community hospitals, the sort of flipside of the coin for [the stroke specialist nurse] up there [at Victoria Hospital]... Their role would be making sure the right patients are in the community hospital bed and liaising with [the stroke*

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*nurse at Victoria], the consultant and all the rest of it. So yes it's impossible for one person. Like I say, in an ideal world what we would like to do is to have members of the [community hospital] team go up there to assess people. The next best thing...we could have another [stroke nurse] and have better communication and let that person up there make the judgement in the absence of us being able to go up.*

Another interviewee also argued that greater autonomy for the stroke specialist nurse would bring about improvements in continuity as follows:

*I genuinely, passionately believe that once we get a ward [for rehabilitation] that is purely stroke here, we will be able to end up with this constant play through... [Then] what we ideally would like is for [the stroke specialist nurse] to be able to walk around the hospital [Victoria] and say 'Well yes that patient will do well in the Gloucester Unit so send them'. But no it has to be a doctor say so. So if he is on holiday or away for a couple of days then the patient stays where they are. In the meantime, they will probably end up being moved to save this more lost soul or wherever there is an empty bed... I think if we could address that then literally the continuity of care for a stroke patient I think would be vastly improved.*

As already noted, from the community hospital point of view, the main criterion for transferring patients from Blackpool Victoria appeared to be the 'weekly bed crisis', which meant that at the Gloucester Unit in particular there was a perception that 'We get a significant number of inappropriate patients'. Here, moving all stroke patients on to a single ward and giving an extended and more significant role for a stroke specialist nurse in terms of co-ordinating transfers from Blackpool Victoria were seen as potential improvements.

In South Tyneside, once again, it can be argued that relative organisational simplicity alone creates the conditions for a different role to be played by the stroke specialist nurse. It is unquestionably the case that in South Tyneside she did play a different, more extended role. Here the genesis of the role was significant. Created before the appointment in 2003 of a specialist stroke consultant, the stroke specialist nurse played an important role not just on the specialist Stroke Rehabilitation Unit but – as in the other two localities – in co-ordinating advice to staff and patients outside the unit. It was evident from planning documents, from observation of MDTs and other planning meetings and from interviews with staff, patients and carers that the stroke specialist nurse plays a pivotal and notable role not just in horizontal co-ordination and integration across the patient journey but in the vertical integration of strategic planning and operational service delivery. According to one colleague (in 2003):

*The huge difference came when [she] got her post a couple of years ago, because there wasn't really anybody to pull things together... The advice, there was none of that; and the information, I think that has improved massively since she had her role [as stroke specialist nurse]... The difference that made over on Medicine was massive in terms of the patients getting good information and good management. Because as a specialist nurse she was going in and advising the nursing staff that they need this and this. And the medical team quite often weren't following the protocol for stroke; and she was that link.*

Clearly operating, *de facto*, as stroke co-ordinator the vertical integration included, for example, chairing the LIT Standard 5 (Stroke) sub-group, making successive business cases for service development and investment, co-ordinating production of the stroke care pathway and leading successive (successful) applications for Charter Mark status – the latest in 2004. The

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horizontal co-ordination extended either side of patients' hospital stay: from TIA clinics to undertaking home visits post-discharge to check patients' medication, progress with therapy, mood and general social support. The stroke specialist nurse also conducts, together with medical colleagues, review clinics approximately 6 months post-discharge. Whereas it was generally acknowledged that some of this role – including unofficial stroke service champion – would be shared with the newly appointed stroke consultant it was also a widely held view that the current post-holder personified the commitment of the whole team to continuity of care. Patients and carers – understandably, given their perspective – seemed to take for granted the continuity provided by a single specialist acting in this capacity; but they were invariably extremely complimentary about the way the stroke specialist nurse embodied such continuity of care.

### **4.3.7 Summary**

In all the published guidance there is clarity about the need for people who have had a stroke to be admitted as soon as possible to a specialist stroke unit. Although it is less clear precisely what such a unit should comprise, it is defined in the most recent (2004) Royal College of Physicians' Sentinel Audit as 'a multi-disciplinary team including specialist nursing staff based in a discrete ward which has been designated for stroke patients' (Royal College of Physicians, 2004, Concise Report, p. ix). Such a unit, by this same definition, might comprise an acute unit, rehabilitation unit or a combined acute and rehabilitation unit. Among five criteria used as markers of stroke unit organisation by the Sentinel Audit were the existence of a consultant physician with responsibility for stroke and the existence of multi-disciplinary meetings at least weekly to plan patient care.

The NSF for Older People (Standard 5) states the Government's aim as being 'to reduce the incidence of stroke in the population and ensure that those who have had a stroke have prompt access to integrated stroke care services' (Department of Health, 2001b, p.61). Interestingly, whereas the Sentinel Audit is focused primarily on the hospital-based unit, the NSF spells out four main components for the development of integrated stroke services, one of which is 'long-term support'. The Sentinel Audit, too – in each of the biennial audits since 1998 – has asked about the existence of Community Stroke Teams; but only in the 2004 audit were sites asked whether they have Early Supported Discharge Teams (Royal College of Physicians, 2004). There is, according to the report, 'as yet no definitions as to the constitution of an ideal early supported discharge team'. But the report notes the regular membership of such teams; in the 16% of sites with such a team, social workers were regular members on only 38% of them; a figure considerably higher than clinical psychologists, however, who were regular members of only 8% of the teams. Interestingly the report continues by saying that 'the research evidence suggests that medical, nursing and therapy input are all desirable' (ibid, p.21). The latter is unsurprising, but what is interesting in the context of this study is that there is no mention of social worker or clinical psychology input. This despite the audit report's clear message that 'effective longer term management of patients after discharge from hospital is critical as patients can continue to benefit from rehabilitation and to help with reintegration for a prolonged period after stroke' (ibid, p.20). The report also refers to the need

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'to transfer the care of stroke patients from hospital to community and not to "discharge"' (ibid), thus implicitly underlining the importance of transfer to both local-authority social care and community/primary healthcare.

As we have indicated in this section there is a lack of clear guidance about what constitutes an integrated and specialist stroke service across the whole patient journey; that is, primary, secondary (acute) community and domiciliary settings. The specialist provision across the three study localities was limited: a 20-bed acute unit at Blackpool Victoria Hospital, with a 20-bedded stroke and neurological rehabilitation unit on ward 2 (the Gloucester Unit) at Clifton Hospital, Lytham; and a 16-bedded Stroke Rehabilitation Unit (with specialist clinical, nursing and therapy staff) at South Tyneside General Hospital, together with a small Community Stroke Team and – as agreed towards the end of our fieldwork – the imminent creation of four acute stroke monitoring beds. In Darlington the stroke rehabilitation programme was run on six beds in a general medical ward. Partly because of the wider stroke service redesign consequent upon the Darzi review there was no specialist stroke acute or community service. Moreover, within the stroke rehabilitation programme, apart from the stroke specialist nurse (this itself a half-time post), there was no dedicated stroke staffing resource.

In addition to the question of whether they are a full-time dedicated stroke resource, the other important aspect of specialist stroke teams is their composition in terms of range of disciplines and interests. Two of the teams (South Tyneside and Lancashire) had a specialist stroke consultant, one (South Tyneside) had a clinical psychologist (0.5 wte on the stroke rehabilitation team) and none had attached social workers or social workers who regularly attended MDTs. Given the focus of this study on the hinge point of hospital discharge, social work input to specialist stroke services and the relationship between health and social care professionals in general were of particular interest in terms of their ability to work in partnership to ensure continuity of care across this crucial point of transfer. We found several areas of concern. First, social workers not being able to attend MDTs was said by health-service colleagues to be unfortunate in terms of continuity of care (a) because they had no first-hand knowledge of patient progress and needs over several months, (b) because their planning for discharge and post-discharge support was later and less well informed and (c) because as a result they often therefore sought further assessments of patients progress and potential at the time of discharge. The latter was thought by health-service staff to impose an unnecessary discontinuity: why should a patient who, for example, had been on a stroke rehabilitation programme for 2 or 3 months have to be assessed again by another professional – the members of the stroke team had by this stage made a full assessment based on their full knowledge of the patient's accomplishments, potential and needs. The second, related area of concern was differences in view about post-discharge destinations for patients. Health staff often thought that the wish of social services to consider intermediate care was at times an unnecessary two-stage transition for patients they judged to require a care-home placement. Social services, however, took the view that health colleagues often were too risk-averse and should encourage some intermediate point of rehabilitation if (a) it enabled patients to leave hospital earlier and (b) gave them the chance to go home with domiciliary support rather than into long-term care.

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We looked into inter-professional working within the stroke service teams and found evidence of some excellent inter-disciplinary working – a product of which was a real sense of continuity for patients as they were cared for by different team members as members of a single team not as members of separate professions. Such collectivity extended in spirit but not in practice to patient record keeping, where a combination of the practicalities of keeping single paper records and, in Lancashire, the complexities of a multiplicity of geographically dispersed agencies, impeded the development of a single, complete patient record which travels with the patient across the various component parts of their journey.

One important way in which such continuity was sought in each of the three case-study localities was through the stroke specialist nurse. In each case the post-holder significantly affected the co-ordination of treatment, rehabilitation and care for patients. In Lancashire, due to the complexity, geographical dispersal and size of the service this co-ordinating function was largely confined to the acute hospital. In Darlington the half-time post led to a similarly restricted remit within the hospital. In South Tyneside, by contrast, the stroke specialist nurse acted as stroke co-ordinator across the whole patient journey and in all settings – in TIA clinics, on the acute medical ward, on the Stroke Rehabilitation Unit and in their own homes post-discharge. Partly a function of inter-organisational simplicity, this was also partly a function of history and personality: someone who had been a stable staff presence (and point of continuity) for several years before the appointment of a specialist stroke consultant; someone, too, who played a pivotal role not only in horizontal co-ordination and integration but in the vertical integration of strategic planning and operational service delivery. Someone, also, who was widely said to embody the Specialist Stroke Team's commitment to continuity of care across a well-developed, integrated set of services.

### ***4.4 Experienced continuity of care across the patient journey***

#### **4.4.1 Introduction**

It is important to stress that in those parts of this section which comprise a description and analysis of patients' (and carers') accounts of patient journeys there is often an apparent imbalance such that adversely critical comments and accounts – merely by virtue of their length – appear to outweigh approbation and praise. This is in many ways neither surprising nor unusual. When asked for their views, patients – in this study no less than many others – typically are generous in their praise of the treatment and care they receive; but they rarely say so at length. On the contrary, as we shall see, they often say something like: 'they [doctor/nurses/therapists] were wonderful, what more can I say'. Of course, when gently pressed they can say in greater detail what was wonderful and why. But it is a simple observation that such statements are usually much briefer than recollections of perceived difficulties and problems. This is not, of course, invariably the case: the rare very bad experience is often just too difficult to talk about. It is, however, a general rule that people laud in brief but criticise at length. In so far as this report reflects this imbalance in the accounts given by the patients and carers



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recruited for the study it does so in order to highlight problems – whether individually or generally perceived – from which lessons can be drawn for future service development. Although equally important for service design and development, it may be sufficient to record praise in brief, whereas perceived problems need to be spelt out at some length. But to repeat the point about imbalance, it is important that the critical comments and accounts, however lengthy, are seen in the context of general and genuine admiration, praise and gratitude for the treatment, rehabilitation and care received throughout patients' care pathways. It is worth adding that there is no reason to think that the people who agreed to take part in this study were predisposed to be generous in either their praise or blame.

One of the principal benefits of in-depth, face-to-face interviews as a research method is not only that service recipients have an obviously unique perspective on service delivery but that they can give a detailed, fine-grained and layered account of their experiences. Other methods, such as questionnaires, are by contrast course-grained and two-dimensional. As well as their inherent richness, however, interviews take place at a particular time and are inevitably coloured by proximate experiences – however apparently mundane or even trivial in the context of their overall care. This, in part, is why it is important to interview patients – as in this study – over a long period, covering their time in hospital and post-discharge. Apart from anything else this allows interviewees cumulatively to reflect upon and put in perspective their whole experience.

It quickly becomes apparent when interviewing patients about those aspects of their treatment, rehabilitation and care which promote or impede continuity or seamlessness that the apparently incidental can sometimes seem extremely important. As we shall see, continuity in terms of the removal of worries about family or small irritations about some ward routine can at times be seen as significant. Our interviews were based on a topic guide (see Appendix 2) designed to reflect the major factors – structural and procedural, organisational and professional – which affect continuity of care. This included a series of questions, with suitable prompts, not just about *what* the care comprised but about *how* treatment, rehabilitation and care is given. We know from previous research (and, indeed, common sense) that how care is given is as important as what is given. Thus it is little good patients – as questioned in this case – being given intensive therapy or copious amounts of information or being closely involved in discharge planning if this is done in a way they think is brusque, or impersonal, or thoughtless or hurried; or if it is done in a physical environment perceived to be too dirty, too noisy, too hot or too cold. This is simply to make the point that environment, atmosphere and the personal approach of staff can be as important aspects of perceived continuity as how well co-ordinated is an agreed programme of treatment and care. Thus, in the language of the NHS Plan, the NSF for Older People and much other national guidance, continuity of care will be the product as much of a patient-centred approach and the general hospital environment as of adherence to any care pathway or model of care whether emanating from Royal College guidelines, the NSF or elsewhere.

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### **4.4.2 Information and involvement**

The Royal College of Physicians' Sentinel Audit asks about various aspects of 'communications with patients and carers', including patients' access to their management plans, patient information literature displayed on the ward, the existence of formal links to patients' and carers' organisations and the existence of a community user group for stroke. South Tyneside's Stroke Rehabilitation Unit scored well in 2004 on almost all these service characteristics – and, in line with an overall improvement nationally, scored better in most than at the time of the last Sentinel Audit (in 2002).

In our study in South Tyneside patients and carers, without exception, praised the amount, range and timeliness of the information they were given. It is, of course, important to note that the information available on the Stroke Rehabilitation Unit itself is not so readily available on the general medical and assessment wards. It would be impossible, or at least impractical, for such wards to have available specialist literature on all conditions – CHD, diabetes, stroke, etc. What matters is that someone on a general ward has such information as and when they require it. One of the recruited patients in this study, when asked on a general medical ward whether there was any information he would have liked but hadn't had, or anything he felt he hadn't been told, replied: 'no, at present I think I understand what's happening to me. And I understand what they are trying to do. I think they do a damned good job'. He said that he had had a visit from the stroke specialist nurse and been told, among other things, that he was a good candidate for the Stroke Rehabilitation Unit and would be moved there as soon as there was a bed. He also said that his wife had watched the stroke video produced by the Stroke Rehabilitation Unit and 'found it very useful'. This, indeed, was a view echoed by all the patients and carers. Each had at sometime watched the stroke video and each found it extremely useful. The same patient also referred enthusiastically to the Monday afternoon Adjustment Group for patients and carers. 'There is', he said, 'quite a lot of information' from voluntary agencies attending the group, and in general 'loads of information'. Other patients, too, spoke of having 'all the information I need'; and having been told 'everything they wanted to know'. In speaking highly of such information the patients and carers were talking, apart from the stroke video, about the range of pamphlets dealing with all aspects of stroke as a condition, relevant local organisations and associated available help (e.g. with welfare benefits). One set of information included in the Sentinel Audit which was not available in any of the three localities was that relating to patient versions of national and local standards. It has to be said that as well as being fairly easy to rectify this was not a gap commented upon by any patient or their carer.

What was commented upon, as we discuss below, were details of some of the information and how this was communicated; particularly about what would take place before, at the time of, and after hospital discharge. Clearly any audit (such as the Royal College of Physicians' Sentinel Audit) can more readily ask about, record and quantify whether or not, for example, patient information literature is displayed about 'social Services local community care arrangements'. The answer is a straightforward 'yes' or 'no'. This, however, obviously records nothing about either the quality of the information (its comprehensiveness, clarity, currency, reliability, etc.) or the quality of any

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discussion about that information – for example, under what circumstances services are available or not and to whom.

We asked both patients and carers about the extent to which they were involved by staff in discussions about their goals (long and short-term), their treatment and rehabilitation programmes and plans for discharge and subsequent service provision. Patients invariably were positive about their involvement in discussions about treatment and rehabilitation goals. This was often a painful process because for some such discussion involves a growing realisation that 'getting back to the way I was before I had my stroke' is an unrealistic goal. The general impression was of staff urging both realism and ambition; and of them urging patients to achieve their optimal potential – often more than patients themselves initially thought possible – without being harried or hurried. And, moreover, of doing all this in genuine consultation with the patients.

One other important question we asked was about carers' perceived involvement in what was happening to their family member. This was possible for four of the seven recruited patients in South Tyneside. These carers included two wives, one son and one daughter-in-law. Neither of the last two lived with their family members and only one lived nearby. According to one of these four carers she was certainly involved in discussions prior to discharge with nursing staff and the social worker 'who rang me up and spoke to me on several occasions about what were the best options. So I didn't feel as though there was a problem there at all'. Asked if there would be any changes she would recommend, she gave the following succinct blueprint for ensuring continuity of care at the point of hospital discharge.

*Obviously it's important for patients' carers and immediate family to be au fait with everything that's happening and to be part of this decision as to what's happening. And also, to ensure that social services or whoever is taking over have contact with the family immediately so there is not a gap. I think it's important there is no gap between the end of the care in the hospital and what's happening there. Having said that, I am not criticising and saying this didn't happen because I felt as though it did; but to ensure that that is always there. And also the follow-up from the carers or whoever it was in hospital.*

Another of the carers spoke warmly of time spent in the Stroke Rehabilitation Unit gym with the physiotherapists learning how to help with standing, transfers and walking. According to the patient his wife had been worried 'in case she was struggling a bit'. But she was shown how to provide assistance and as a result 'was really pleased last night when she went home' because of her new-found confidence. Another carer praised simultaneously the carers' group run on the unit and the information given to carers. 'They are very good. I came to this carers' meeting the other day at which they explained all about aids for the house and they had all these pamphlets. Which were great, they are all there'.

In the other two localities there were no comparable carers or patients groups. When asked, this was said by only one of the five recruited patients in Darlington to be something she missed. It would, she said, be nice to share with other patients their experiences of stroke and associated hopes and apprehensions. All five patients spoke of being well informed and, in so far as they wanted to be, of being closely involved in their care planning. According to one: 'Everything was explained to me. I knew what was happening...people

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do talk to you and tell you what's going on and discuss goals with you.' For all patients on the stroke rehabilitation programme on ward 41 a lot of information was available and staff held regular meetings with patients and their carers to discuss care planning (including goal setting), progress made, potential discharge dates and, when discharge was imminent, detailed planning and after-care arrangements. A lot of relatives came into the ward to participate in care. Where patients who were being discharged were going to be heavily dependent initially upon care support staff 'ask the carers to come in and participate so many mornings a week so that they know what to do and to keep it going'. But this was only for patients on the stroke rehabilitation programme, not for patients being discharged from other wards. Similarly, for patients on other medical wards, the stroke specialist nurse would talk to patients and leave information (including the Stroke Association video) for carers about, among other things, local voluntary-sector services and advice and support groups.

In Lancashire (Fylde and Wyre) also, the stroke specialist nurse (based at Blackpool Victoria) was vital. A typical carer comment was: 'She went through everything with us, she was very thorough in her explanation of what to expect, what not to expect'. However, three of the patients in the study were on ward 20 when the stroke specialist nurse was on leave, and there was a noticeable contrast in how much they felt they knew or had understood about what was happening to them. According to one: 'No. I don't know if they have spoken to my daughters, but I don't think anybody has spoken to me. What are they going to do? What am I going to do myself? Am I stopping here or are we going to Fleetwood or what?'. Although leaflets were available on the ward for relatives to pick up, without the stroke specialist nurse pointing them out not everybody noticed them (and other nursing staff had, it was said, not provided leaflets or detailed verbal information when the stroke specialist nurse was away). As one family member commented: 'At the Vic to be honest I didn't even look for leaflets because I personally was traumatised. I'd had enough'. By contrast, the stroke specialist nurse 'gave us lots of leaflets'.

Patients and families in general also felt there was a lack of ongoing information on their progress and treatment at the community hospitals. This was particularly the case on wards caring for older people in general and not specialising in stroke rehabilitation. This compounded their lack of information if they had not seen the stroke specialist nurse at Blackpool Victoria. The following comment was typical.

*They haven't said anything really [in terms of information about stroke]. They don't give you any information about what caused a stroke or anything like that. They don't talk to you; the staff don't talk to you about the effects of a stroke on the body... Nobody gave me a leaflet. Nobody gave me anything, it was all given by outside help.*

The lack of access to a staff member (stroke specialist nurse or similar) with a remit and, perhaps more importantly, time to focus and not be 'pulled away' for more pressing 'nursing' tasks is important because some families were clear that they needed a 'second chance' to get the information they wanted. This was mainly because in the patient's acute phase at Blackpool Victoria they were still 'in shock' and not ready to 'take in' what they were being told. As one said: 'She [the stroke specialist nurse] explained it [but] I think it was just because I didn't want to know I didn't ask any questions'. By the time

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patients had been transferred to the community hospitals, however, they and their families were beginning to understand their situation and felt better placed to ask questions.

This underlines the importance, in the absence of the stroke specialist nurse at Blackpool Victoria (and the general lack of such focused support at the community hospitals), of the role of the medical staff at ward rounds, and the involvement of patients and families in regular progress meetings. All of the patients and families included in the study commented on how informative and generally supportive the consultants had been when they had requested an individual meeting (not all patients felt able to ask questions in front of other patients on the ward during routine ward rounds). But the stroke consultants were not available at all of the community hospitals; nor were they equally available on different wards within the same hospital (e.g. Blackpool Victoria and Clifton). In addition, few of the hospitals and wards hold regular review meetings involving patients and families. As one patient commented: 'I suppose I must be progressing. They must be talking about you somewhere, without me knowing'.

In an interesting echo of a problem mentioned by other patients across the study localities (see below) it was said in Lancashire that although the charge nurse and other nurses on ward 20 at Blackpool Victoria and at Clifton were 'very nice' and had been helpful and informative when approached 'they don't have much time, they are very busy' and 'They are very short of staff as well'. In other words patients had not wanted to 'waste the time' of the nurses to ask everything they wanted. Interestingly, the expectation of one patient before being moved to the community hospital (subsequently not met) had been that:

*...[at the Gloucester Unit] there is more time, as I say the staff will have more time to talk to us because they are not running off to and emergency and buzzers aren't going every five minutes. It should be a lot easier to cope with that.*

By contrast, the experience of the one patient who was transferred to intermediate care was of regular diaries progress meetings involving himself, his two key workers, the home manager, social worker, occupational therapist, physiotherapist and nurses. He said:

*...[at Clifton I felt] isolated, yes. You at least get answers here... So there are lots of people there [at the meetings in intermediate care] and they are all giving inputs about how I am doing... [And] you get the chance to come in if you want. You are there when they are doing it, you come in, if they are discussing and you want to say something you come in.*

There is here a question about patients' and families' expectations. Commonly, across the three localities, they said that they had wanted firm time frames in terms of prognosis and likely progress of rehabilitation, but that they had been told this was difficult 'because all strokes are different'. The advantage that patients have on a larger specialist stroke unit – especially a rehabilitation (or combined) unit – is the opportunity to take part in the sort of patients and carers groups that are inherently more difficult to organise and run in a smaller, non-specialist, less well-resourced or geographically dispersed service. In South Tyneside, for example, we have noted the enthusiasm of patients for such groups, including the Adjustment Group organised and run by the clinical psychologist. The importance of these

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groups – to patients and carers alike – was precisely that they could share information with individuals and their families. As one patient remarked, 'we are the real experts'. Here there was said to be honest and frank discussion of a sort that was rarely possible with staff, however honest and frank and informative they were. We were told of one memorably galvanising contribution by an ex-patient of the Stroke Rehabilitation Unit at South Tyneside. This was a young man who, having had a dense stroke, had improved dramatically over the course of months of inpatient and outpatient treatment and rehabilitation. He was able to talk to patients in the group with, at times, startling frankness: 'why were they sitting around moaning and being so pessimistic?'; 'why weren't they trying harder with the therapy exercises?'. As both staff and patients commented, only he could talk to patients in this way. This was information (and encouragement) of a different order to that contained in leaflets, or even in an excellent video.

### **4.4.3 Transfers within hospital**

The consensus in all the available guidelines – in Europe and Scotland as well as England – is that someone who has had a stroke should have immediate access to a specialist stroke service. And whereas the widely acknowledged gold-standard specialist service would extend into primary care and encompass the ambulance service, the prime concern for most localities (in line with the NSF) is in having a specialist unit within hospital. As discussed above, there is scope for debate about whether such a unit should comprise both acute and rehabilitation beds and whether they should be combined. What is not disputed is that certain clinical procedures, clearly laid down in Royal College of Physicians' guidelines, are crucial to the successful early diagnosis and initial treatment of stroke and that these will best be provided by staff with specialist stroke knowledge and training – especially clinical and nursing staff but also speech and language therapists – working together in a dedicated acute stroke unit. In neither Darlington nor South Tyneside was such a specialist acute stroke unit available during this study; although, importantly, in South Tyneside four dedicated acute stroke beds on a general medical ward had been agreed and funded towards the end of our fieldwork. In both localities the stroke patient's typical initial pathway – dependent, of course, on the severity of their stroke – was from A&E to medical assessment unit to general medical ward. After the initial- non-specialist – acute phase in each hospital some would then transfer to the stroke rehabilitation programme beds in Darlington (six dedicated stroke beds on a general medical ward) or the 16-bedded specialist Stroke Rehabilitation Unit in South Tyneside. In either case, since places available in these specialist beds were limited, people would inevitably have to wait on the general medical wards during part of their acute phase. In terms of continuity of care there are two significant features of this aspect of the patient journey. First, and most obviously, the series of transfers between wards represents a transition from one location to another. Each represents not just a physical relocation but a change in staff, in the ward environment (and, possibly, ward procedures and protocols) and, possibly, in care regimes and expectations. In other words, transfers between wards (and even more so between hospitals) constitute potentially significant discontinuities – with changes simultaneously in the environment, staff and the content and processes of care. The second aspect is the nature of the rehabilitation received on general wards and the effect

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upon patients of having to wait for an unpredictable length of the time for specialist stroke rehabilitation.

One patient in South Tyneside recalled spending 6 hours in A&E (because the hospital was very busy), within which time, he said, 'The nurses and doctors had done everything that had to be done as regards tests...so eventually I got up to ward 7 [at approximately 9.00 pm on a Tuesday evening] which is an assessment ward. I was a day in there and they found out what things were like. I was taken down on the Thursday to get a brain scan and the doctors came round and told us that I was lucky in one respect because the brain showed no damage whatsoever...and until a bed was available I stopped on ward 7. Until about 5.30 on a Friday afternoon when I was transferred to this ward [the Stroke Rehabilitation Unit]'. He said he had been told that staff would try to get him across to the unit sooner but there were no vacancies at the time. He then echoed what others often said (see below), that 'with it being a Friday naturally the physios and that finished. And I saw a young lady who introduced herself to me and said "we will get the ball rolling on the Monday"'. Had he been able to get to the unit sooner, he said, he 'could have possibly had therapy Thursday and Friday'. 'But', he added, 'I could never say I wasn't attended to. I was given full attention and full treatment as much as they *could*'. He was also full of praise for the way in which he was moved from the assessment ward to the Stroke Rehabilitation Unit. Having been told on the Friday morning that there was a vacancy on the unit and that he would probably be moved sometime over the weekend, the charge nurse came at 5.00 pm on the Friday and said 'we are moving you now, get your things together...and I was wheeled over straightaway. All done and dusted in 20 minutes...so I have been here and I have found it very very good'. This he thought represented a smooth handover and seamless transfer from ward to ward:

*Q: So the transfer itself couldn't have been smoother?.*

*A: It couldn't, no. Nothing traumatic about it at all, no.*

*Q: And what was the introduction when you got on the unit in terms of 'this is who we are, this is what we do'?*

*A: Oh very good. Of course it was a Friday night so there was no therapists here; it was just the nurses and the sister. Somebody in the team introduced themselves and the team leader and a nurse.*

A similar key issue at Blackpool Victoria Hospital highlighted by NHS managers and staff was the fact that not all stroke patients were admitted directly to the stroke specialist ward 20. The view was that such patients receive a different level of support and care as a result. This was confirmed by patients and families interviewed. The three patients admitted via A&E and the medical assessment unit straight to ward 20 said 'The transition was brilliant. No complaints whatever'. By contrast, the experience of being admitted to a non-stroke ward (which had locked doors and so felt much less accessible than ward 20) after A&E was less satisfactory. As one carer remarked, her husband 'didn't stay there long and the staff were not very communicative and they seemed very busy all the time and then they moved him to ward 20'. Furthermore:

*One of the worst things, on the Sunday morning after they had admitted him on the Saturday and said they couldn't find anything wrong, I rang Victoria*

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*Hospital about 7.30 in the morning and I said 'Can you tell me how he is?', 'Oh he's fine'. So we went up at 12.00 thinking, well things were the same, to be greeted by him all being pulled down the one side. Now that was an awful shock... [Then] of course he was worrying himself sick when he'd realised he'd had a stroke. He got himself into a real state about the fact that...they hadn't got round to putting any stockings [to stop blood clots] on him and he was convinced he was going to have another stroke... It was really quite upsetting to see how frightened he really was. But once he moved down to the stroke ward and his stockings were put on and he was in a proper stroke bed he was fine – a lot more comfortable knowing that they were doing as much as they could for him... Yes I think had he gone onto the stroke ward straightaway that would have been better for him.*

For these patients not admitted to ward 20 being visited by the stroke specialist nurse on the other wards was vital to feeling secure and knowing what was happening to them. A typical comment was:

*She was the stroke co-ordinator. She doesn't actually nurse on the ward but she does co-ordinate the movement of patients from other wards onto the stroke ward... She was very reassuring wasn't she? ... Very, very good, very, very good facilitator that, having a co-ordinator.*

Whether among the group of patients recruited to this study or in observation of MDTs we also saw examples in South Tyneside of patients moved from stroke rehabilitation beds to other wards prior to their discharge. These were of two types – each, it should be said, few in number. First, patients moved near to their point of discharge because of some 'red alert' pressure on beds. Second, patients who, for whatever reason, cannot sustain intensive rehabilitation.

### **Transfer upon reaching a plateau**

The latter inability to sustain intensive rehabilitation may be because patients have reached a plateau in terms of their recovery, or because they have deteriorated – whether due to stroke extension or other illnesses, or because they have low motivation. In each circumstance there is a potentially difficult decision about whether and when to move someone out of the stroke rehabilitation beds. It is a difficulty made more pressing if there is someone else occupying a bed on a medial ward who would be expected to benefit significantly from the intensive specialist rehabilitation available only on the stroke rehabilitation beds. Asked how for the first of these cases that sort of transfer was undertaken, a stroke unit ward sister replied:

*It is obviously quite difficult because when they come here both the patient and the family have high expectations that, obviously, if they're coming here they're going to make some improvements...it's about preparing them a week or so beforehand, saying 'this is the progress that you've made, this is very good, but you're probably not going to progress that much further.'*

But, she said, even more important was to talk honestly to the patient and their family as soon as they arrived on the unit: to be optimistic but realistic; to offer every possible encouragement but never promise a particular level of recovery; and from day one 'not to give them false hope and not to demoralise them'. If a close, honest, relationship is established with the patient and family from the outset, later transfer, it was said, is rarely problematic. Moreover 'often I don't think it's because they are worried about



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getting less rehabilitation. I think they have just got so very used to being here and they feel quite safe here and it's a new move'.

*Q: But it's also formal confirmation that there is a plateau being reached here?*

*A: Yes, it's something you [the patient] have got to face up to.*

In similar vein it was argued that although there was no age policy operating in any of the sites, 'if you had a 40-year-old sitting waiting to come here [to a Stroke Rehabilitation Unit] and someone who is 86 and she is not doing anything what would you do? It's priorities'.

Much more common in this study was the transfer of patients from medical assessment unit to medical ward and from medical ward to stroke rehabilitation ward. As one member of the team in South Tyneside remarked 'I don't like them being moved around: that is one of the worst things that can happen to people who have had strokes, being moved around'. In the case of South Tyneside the second Sentinel Audit had showed that some stroke patients spent time on more than five wards. There was here a determination to address this problem and minimise the number of transfers: 'if we are trying to improve the service we have got to make sure that we don't have them going on more wards again'.

### **Transfer due to bed pressures ('red alert')**

In the case of one of the recruited patients there was a marked contrast between the experience of transfer shortly after admission and just before discharge. It was the patient's carer who recalled both experiences. The following was her description of the patient's admission.

*I went down to the hospital and she was down in A&E Department. They were very good and they admitted her up to the admissions ward, ward 7 I think it is. The staff were excellent, I couldn't fault them. She was in there for about 24 hours I think and they transferred her to a different [medical] ward. They said she had the stroke and she was going to the Stroke Rehabilitation Unit, but that was full and we had to wait for a place there. So there was about 3 or 4 days before she was admitted there. When she first went in she said 'I don't like it in here'. But that was because she had been in another ward and she just got used to the surroundings and the staff, as you do. I said 'oh, you will be fine'...and she was – within a day or so she was settled in. And they did make her feel very special and welcome the staff, they really did and she enjoyed it.*

After 14 weeks on the Stroke Rehabilitation Unit the patient was ready to be discharged to her former sheltered accommodation. With one exception this discharge was, according to her carer, handled extremely well. The exception was a ward transfer made – because of a 'red alert' – on the patient's last day in hospital: once again recalled by the carer as follows.

*They put her out of the ward [the Stroke Rehabilitation Unit] to another ward. I can't remember what it was, it seemed very isolated...I think it was the afternoon before, you know the day before she was due to be discharged that she went there. And I went up there to see it, it was quite strange because there were two other ladies in there, but they were both waiting to be discharged that day, they were waiting for transport to take them home. I think that was a bit distressing for her. When she moved out of ward 8 or whichever ward she had been moved into after the admissions ward she was just in for 2 or 3 days until this place became vacant on the Stroke Rehabilitation Unit. She had got used to being in there even though it was a fairly short time then when she moved into the Stroke Rehabilitation Unit she said 'I don't like it in here'*

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*because it was different and there was different staff and that sort of thing. But she soon got to like it and the people who were in there were nice and the staff were fantastic with her. But then for this last day to be moved out, I mean I found that a bit strange for the sake of 1 day why she had to be moved out and entirely different staff. I mean, nice staff, but different. So that wasn't such a good thing, no. Because all her stuff had to be moved up. I mean she had quite a lot of stuff in the week she had been in so it was all moved up in black bags. It wasn't terribly satisfactory.*

*Q: And was it unexpected?*

*A: I certainly didn't know and I had been down the day before. I came down the following day and went down to the stroke unit and they said 'oh they have moved her up to ward 21 before she is discharged tomorrow'...that wasn't a positive thing I have to say, no it wasn't good.*

*Q: Did she take it in her stride?*

*A: Oh she didn't like it: 'I don't like it in here'. I don't know if she was actually on the ward alone overnight because the two ladies that were in there did go that day; so she was probably in there on her own that night. And she wouldn't have liked that at all.*

*Q: But it didn't typify the rest of the time?*

*A: Oh no, by no means.*

Just prior to this series of recollections the carer had summarised the care given as being faultless: 'can't fault the care she had in hospital, everybody was very caring with her and the medical care was obviously good. The physio side of thing was good. Social services when they came out they had been excellent. In the care home where she was the staff there were superb.'

There are some important points to make about this set of recollections. First, it simply underlines the importance of physical transfers within the pathway of treatment, rehabilitation and care. They involve a literal disruption (i.e. an interruption in the flow and continuity of care). Sometimes, of course, transfers are necessary and desirable – and are acknowledged as such by patients and carers alike. For example, when patients who are taken ill a long way from home. Although there were no such cases in the patients recruited in this site there were in one of the other sites; and among non-recruited patients in South Tyneside. Such patients almost invariably wish to be transferred to care within their home locality. Another transfer widely accepted as appropriate by recruited patients was from assessment ward and medical ward to the Stroke Rehabilitation Unit. In other localities – albeit, as the most recent Sentinel Audit shows, not commonplace – patients could expect to be transferred straight from A&E to a specialist acute stroke ward – thus bypassing transfers to assessment or medical wards. In the near future this will be the case for some patients in South Tyneside now that funding has been agreed – both capital and revenue – for four acute stroke beds.

As we have seen, our interviewees were keen to get to the Stroke Rehabilitation Unit but accepted having to wait until a bed was available. And interestingly none described the wait as being a 'delay' or suggested that specialist stroke services should be available from the moment of arrival at hospital – or, indeed, prior to arrival. This, however, is the clear intention behind the Royal College of Physicians' guidelines and NSF targets that all general hospitals have specialist stroke services in place.

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### **Transfer between hospitals**

The transfer from Blackpool Victoria to the various community hospitals was a potential point of major discontinuity for patients and families. Significantly, it was perceived to be smoother – for example, in terms of the amount of warning patients and families had – with the involvement of the stroke specialist nurse; although even then as one said, ‘We didn’t expect him to be moved as soon’. For the other patients, the experience was of the move happening even more suddenly. One patient went for a magnetic resonance imaging (MRI) scan and when she arrived back on ward 20 was moved with ‘no warning’. In this case, the patient reported that her clothes were ‘lost’ in the move and she spent ‘2 days wearing other people’s clothes’ on arrival at the community hospital. For another patient, it was:

*...teatime on Saturday, they packed his tea up and brought him here... ‘Take your sandwich with you, go on’... I don’t know whether they had only just found out or they had known for a bit... He was only half way through his sandwich and we said ‘Find us a napkin and we’ll take it with us.’*

For a third patient, transfer to a community hospital had been considered unnecessary because she had recovered so well. However, there was no occupational therapist available at Blackpool Victoria to do a home assessment so that she could be discharged straight home with social services support. The patient was, therefore, transferred to Clifton – thereby incurring not only an additional transfer but a longer stay within the hospital system merely to await the appropriate assessment.

Unsurprisingly, but very importantly, one factor that affected patients’ and families’ perceptions of continuity of care was the geographical dispersal of the hospital system in Blackpool, Fylde and Wyre, with community hospitals spread several miles apart from the north (Rossall) to south (Clifton) and east (Wesham) of the overall area. Travelling by public transport between home and hospital was considered extremely time consuming and difficult, especially for older relatives who often had to rely on family members being available to drive them. The interviewees were, therefore, appreciative of the clinical team’s efforts to accommodate their wishes in terms of which community hospital they were transferred to. As one said: ‘We live quite near [to Clifton] and my daughter so it will be very convenient’; ‘He [father] was worrying about the travelling up to Victoria with my Mum not driving how was she going to get there, and it’s so much easier [to get to Clifton]; and ‘It’s [Rossall] on the doorstep type thing so it would be better’. In all cases the proximity of hospital to home meant that families found it easier to take patients out, for example, at weekends, which they considered an important part of the recuperation process.

#### **4.4.4 General care within hospital**

In addition to the above-mentioned problems with ward transfers and the discharge process it was interesting that when asked about any perceived gaps or overlaps or other ways in which their care seemed insufficiently co-ordinated/integrated/joined-up several of the recruited patients mentioned one of the following aspects of ‘general life on the ward’: the general environment; the shortage of therapy; and having to wait to be taken to the toilet.

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### **General environment**

In the case of the Gloucester Unit at Clifton Community Hospital, families knew that they might have a long distance to travel from home, but considered the journey worthwhile because of the 'intensive rehabilitation' they understood their relative would receive. They also appreciated the flexibility of the Gloucester Unit's visiting times. On the other general elderly rehabilitation wards also at Clifton, by contrast, visiting times were considered restrictive for relatives with other commitments:

*And of course, because I have to pick up my daughter at 3.30...the visiting was from 3.30 to 5.00 so anybody with children couldn't go in – and then 7.00 until 9.00, so you are putting your children to bed, you couldn't go in during the day... They just think 'Well most of these people have elderly partners', [but it means] nobody else can go and see them. So it was difficult for me to go and visit her.*

One of the main things that patients and families said they liked at the community hospitals was the feeling of 'normality' compared with the busy acute care environment on ward 20 at Blackpool Victoria: wearing day clothes, bringing in personal items such as photos, being on first-name terms with nurses, having proper meals at a dining table, having a bath using the hoist and being able to go out in the garden. All of these things were regarded as important for successful rehabilitation. As one family member said: 'It's all getting back to "normal" where you are just doing things and that has got to be psychologically better I think getting back to normal behaviour, all be it adapting to disabilities'.

However, there were differences in the reported experiences within the community hospitals. The Gloucester Unit in particular was compared favourably with the general elderly rehabilitation wards where one interviewee said people were left with little 'stimulation' (e.g. no music or games). This was especially an issue for stroke patients – because even if physically disabled they are 'still all there' – in an environment with more mentally frail patients. It was also said that even the Gloucester Unit could go further in terms of allowing patients to do things for themselves. One patient made the comparison with intermediate care where, he said: 'It's a lot better [e.g. going to the toilet, getting dressed on his own]. Like at Clifton you weren't allowed to do any of that'.

This comment reflects some broader concerns that were expressed about the community hospitals as a rehabilitation environment. At Clifton, for example, patients and families commented upon the food and the lack of therapy input. This was relevant for all wards, but for the Gloucester Unit particularly it was an issue because patients said they had been led to expect 'intensive' rehabilitation. Typical comments about the food were as follows:

*He might be a brilliant doctor, but he will never do any good there because...the food is no good – and if it's a recuperation centre the first thing you need is decent food.*

*And the other thing is in hospital the food isn't very good so you are trying to build somebody up and the food is inadequate... And those are the sorts of things that – half decent food, clean ward – I think they forget that's what gets people better.*

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### ***Shortage of therapy***

Shortage of therapy was mentioned – and not always in response to a direct question – by four of the seven patients in South Tyneside. According to one, when asked about how smooth he thought his admission and move to a general medical ward had been, said: 'It's been fairly smooth. I think I was a bit despondent or depressed on Monday...because there were no therapists [over the weekend]: so nothing was happening for the first few days'. Asked if he understood why, he replied 'I didn't understand why at the time. I expected 7-day treatment; it doesn't always work out like that'. Another of the patients said simply 'I think it should continue during the weekend'. Although, she said, therapists 'are marvellous...the only trouble is you're going to get half an hour of physiotherapy 5 days a week because they're closed at the weekends, they don't come. Which I don't think is really very good, you're going to stiffen up. Just to have a little bit more'. A third patient, asked while still in hospital if there were any changes he would recommend said: 'A little bit more physio. Mind that might not suit everyone of course'. He also made another point about continuity of care saying that he was keen to have the same physiotherapists after he had been discharged: 'I wanted to continue with the same people if I can rather than get someone new. Because there was one day they said "we'll teach the nurse to support you walking"; and the confidence had gone, I walked badly that day'. The important thing, he said, was 'The continuity of the same people who know what I have done and what my bad parts were and they can improve on them'. The fourth patient who mentioned the lack of weekend therapy, however, put it in a slightly different perspective. He remarked that: 'Physio only works 5 days and on Saturday and Sunday naturally they don't work. But they give us some little things to do over the weekend...when I'm not with them I am doing my exercises just to keep up'. In a subsequent interview he further remarked that: 'I don't think I would have been as quick getting my faculties back if I had just said once a day for 45 minutes they give you physio. But after you've had the physio and you feel a little bit relaxed – because they are getting on to your muscles – I said right, while I'm sitting here it's going to be another 24 hours before I can see them again, so just let's do what they say'.

One interesting difference between the recruited patients on ward 41 at Darlington Memorial Hospital and those elsewhere was the lack of any complaints about a shortage of physiotherapy or occupational therapy. Elsewhere, as indicated above, there was a widely expressed view that therapy services should be available – like medical and nursing care – for 7 days a week, not just between Monday and Friday. In Darlington Hospital there were no such comments about an absence of therapy at weekends. On the contrary, according to one patient, when asked, 'I'm not unhappy about it because I think everybody has got to have a break' (in this case, the staff). But also, from the patients' point of view 'everybody gets perhaps tired if you do things too much all at once...the way I feel is that if you had it every day you would think to yourself oh I've got to go through that again. Whereas, if you have a couple of days off you think oh a little rest and I'll start again'.

*Q: It almost sounds like being at work?*

*A: Yes it is really. Yes it is.*

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It should be stressed that however much like work there was widespread praise for the therapists on ward 41. One patient said simply: 'they are very good to me. I couldn't ask for better people to look after me...I appreciate everything they do for me'. In the view of another of the recruited patients the physiotherapy in particular was 'marvellous...I can't say anything wrong with them, they are marvellous; I can't fault it on ward 41'. Another of the patients spoke in similar terms about the speech and language therapist, noting especially the reassurance she felt in knowing that it was possible to contact someone after she had been discharged home: 'she is very nice and she helped me. I still do the exercises every day. She gave me all the leaflets...she is very nice; so she said if I have any troubles or problems when I go home or anything like that I've just to phone her and she will try to sort them out, so that's something. To know that you can phone somebody is a great help'.

In terms of limited therapy the following comments were typical in respect of the community hospitals in Lancashire.

*I was supposedly to have extended physio. I didn't get any. I think I managed about 10 minutes in 6 or 7 weeks, virtually non-existent... It was hopeless. In hindsight it was hopeless. When you are there you are grateful for what you can get, that you are frightened of complaining too much in case you [don't] get more. But in hindsight it was hopeless.*

*I think he could have had more physio, I certainly do. But I know they haven't got the staff so there's not much we can do about it... I know reading in books they should have physio every day and he has been lucky if he had it once a week.*

*Yes, they just haven't done it [physio] well not enough have they? They should have been doing it every day instead of once a week. It's no good once a week. You're sat in this [wheelchair] 16 or more hours a day, it's no good.*

Raised expectations were less of an issue for patients on the general rehabilitation wards, but there was still a sense of disappointment when 'She said she would come once a week' and that did not happen. One interviewee expressed the view that, notwithstanding short-staffing, patients should not be 'given up on'; they should receive some 'physical encouragement' even if it could not be 'proper' physiotherapy.

*But the lack of physio – my mother has never been shown how to move, they said she was too weak. I am not sure how much is confusion but even the basics or trying to show my Mum how to read again after she had a stroke there has been none of that. There has been no rehab. So what you're saying is, if somebody has had a stroke and they're 80-odd and they are still coming round, that we haven't got the resources. That's what it's down to, there is no money so the resources go to the people who are going to make the best progress and that's what it's about, money and resources.*

A problem with therapy input was also noted at Rossall Hospital where, according to one patient, 'nothing was happening' until 'my daughter she asked them first, when they weren't doing anything with me, she went up to them and said "What are you going to do with my mother?"' But 'once it started' physiotherapy and occupational therapy were 'regular'.

The above comments and reservation clearly contrast with the reported experience of one patient (referred to above) who went to intermediate care. He argued:

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*I am a lot better since i came here [to intermediate care]. They won't let me do too much because they think I'm going to hurt myself, but they let you do more than they did at Clifton, which is what I wanted, physio... [At Clifton] I wasn't getting any physio, not much, once a week, perhaps twice a week. You need to be out of this thing [wheelchair] every day doing something.*

The main difference between the community hospitals and intermediate care in this respect was the use of rehabilitation assistants or other support staff to continue therapy input when professional therapy staff are unavailable (e.g. weekends, holidays and just generally working on other wards). This was considered vital for patients to keep up the momentum and motivation for successful rehabilitation. As the above patient commented: 'They could do with something like that, an intermediary, at Clifton to look after people...getting on with the actual physical bit of it because that takes time, that does take time'. Underlining the importance of this additional support he added:

*Also if you are in bed until 9.00 in the morning say, and then the physios come and say 'Oh we'll take you for physio now', it's no good. You've got to get your legs moving before they start physio*

*Q: Did you feel that they were making judgements when they hadn't really given you a chance?*

*That's right yes. Like they said in the first place 'You'll never walk'. [But in intermediate care]...they put this thing [knee support] on...it's helped a hell of a lot that, but I never had that at Clifton.*

This patient could now stand and move much more than previously.

### **'In a minute'**

When interviewed at home and asked for his recollections of his time in hospital in terms of continuity of care one patient in South Tyneside spoke, with some feeling, of something mentioned at some stage by all the other patients in this locality except one. This was having to wait for someone to take them to the toilet – generally summed up in the phrase 'in a minute' or 'just a minute'. Typically interviewees were keen to explain such a response to a request as understandable in view of the pressures upon and general shortages of nurses. One exception was the patient who recalled asking to go to the toilet on one particular occasion:

*I was desperate to go to the toilet and I had to have a hand to go. She came and said 'can you wait 10 minutes, we're in the middle of a meeting'. To which he replied 'No, I can't wait 10 minutes, that's why I buzzed. I am desperate.'*

At this point he was taken. But, he said, 'It's hard to believe isn't it. If you want to go to the toilet you have got to say 'I want to go to the toilet in 10 minutes time, I better buzz now'...'can you wait 10 minutes, we are in the middle of a meeting, an important meeting'. 'What's more important, patient care or meetings?' Shortly after this the interviewee was keen to stress that 'The stroke unit was very good and therapy in the stroke unit was very good. The general care was fine but it was just this attitude of 'in a minute' and you'd wait and they'd forgotten.'

This is a good illustration of the general caveat made at the outset – that poor experiences, however unrepresentative, are often recalled at much greater length than good experiences. Thus in general the Stroke Rehabilitation Unit

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and the nursing, medical care and therapy within were 'very good'. Though said in few words these far outweigh the lengthily described less-good experiences. This point needs underlining again. Patients and carers appear in effect to be saying – overwhelmingly, and certainly in respect of what they themselves regarded as the most important things – the treatment, rehabilitation and care was outstanding: but precisely because it was, the shortcomings stand out as a vivid, and often vividly recalled, contrast.

Another of the patients to refer to having to wait again spoke of pressures on staff: 'They should have extra staff on because sometimes you've got to wait a long time just to go to the toilet...the famous words here are 'just a tick, just 5 more minutes'. 'But,' she added later 'it's not the nurses' fault, because they don't have time. They've just got to answer the buzzers as they can you know'. Finally, another of the patients referring to the same problem said: 'It's trying to decide when's the best time to go, that's what I find difficult'.

*Q: To make it convenient for the staff.*

*A: Well, yes and possibly for other people.*

In Darlington, as in the other two study localities, patients similarly voiced general praise for the treatment, rehabilitation and care as well as a small number of perceived shortcomings, almost always associated with staff shortages. In terms of general praise the following typified the view of patients on ward 41 at Darlington Memorial Hospital:

*I was straight into ward 41 and I was seen straightaway...but from that moment when I got into that ward I only had to ask for any help, a commode or anything like that and it was there. I really had very good help. And really that's been like that all the way through...I wanted to join the stroke programme because I wanted to get better as soon as possible: it's a very good programme.*

Although these comments typify the general praise of patients, the following view expressed by another patient captures well what was said by many others not only in Darlington but the other study localities:

*They spend all this money on papering, carpeting, curtains and all the lot, its all beautiful. But they haven't spent it on the staff...the staff, that's where the shortage is. And they are in so much hurry that I think, well I can't ring the bell. You are sitting on a commode half an hour, well that's not basic nursing. But its not their fault. Its not their fault at all. And I said to my family I have never known a minute – 'I'll be with you in a minute' – last as long. Minutes get to half an hour.*

According to the same patient 'the basic nursing care has gone'. When asked what that comprised and what it meant in terms of continuity of care the patient replied that it was perhaps two things. First just being able sometimes to sit for 5 or 10 minutes and talk to (and listen to) patients. 'But,' she said, 'they haven't that sort of time. Like myself, it takes two of them to lift me in and out of bed; but how am I going to say this without...they are in a hurry. They are in a hurry because they have to be'. A second thing, she said, was 'little things like "please don't tuck my sheets in because it ties my bed down". I have to try to pull them out myself. They will leave the buzzer over on the locker where I can't reach it. Little things like that...it's very important to the patient you see. I am not complaining'.



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According to another of the patients on ward 41 the general pressure on nursing staff had an effect upon her care within the stroke programme. Interestingly, without prompting, this patient commented upon the beneficial effects of a specialist stroke service and, therefore, upon the benefits that having a specialist stroke unit – rather than stroke beds on a shared general medical ward – would have. 'The only thing is the stroke programme nurses have their own special way of doing things and you abide by that'. However the other nurses not on the stroke programme 'haven't got time sometimes to get you on your feet...there is a special way of doing it and they haven't always got time because they are so short staffed I think. But that's the only thing; as far as anything else they absolutely do it for you. They really are short and they do a wonderful job they really do'.

*Q: What's the difference?*

*A: A specialist unit, I think that's a very good idea. They are nearly there with it now here. But they have to have other nurses to help out. And those nurses are really very good, but not quite in the same capacity as the stroke nurses. The stroke nurses do give you this extra time to stand on your feet and get your hands locked together. Its very good.*

The other nurses, however, 'just haven't quite got the time to take you through it like the stroke nurses. That's the only thing...I am not saying they are failing in their duty or anything like that'. She also said that 'the stroke nurses who have helped me I think they are wonderful, I really do. If they just had more help and a separate stroke unit on its own I think that would be wonderful'.

There are two general points to make about the above recollections. First, that they should – yet again – be seen within the context of widespread satisfaction and praise. Second, however, that they highlight how what may appear to be relatively small issues can seem important when reflecting on the degree to which care is experienced as continuous or not. The two issues are of a different order. The 'absence' of therapy on a weekend might seem unremarkable to staff. But, as two of the carers remarked, you take it for granted that when someone is in hospital there are doctors and nurses to look after them all the time. Why the difference with therapy services? The answer can be couched partly in terms of a necessary 'rest' or in terms of recruitment problems or in terms of resource pressures. Whatever the answer it would seem worthwhile making it clearer to patients and carers from the outset that their rehabilitation will be given by trained therapists from Monday to Friday but that therapy does not end there. First, it will be continued – in terms of exercises being done with and encouraged by nursing staff. Second, it should be continued by patients themselves: indeed not just at weekends but for the rest of the time on the ward when they are not receiving active, hands-on, support from occupational therapists, physiotherapists, speech and language therapists and dieticians.

It is a slightly different issue when the patients (or carers) who are referring to an absence of therapy at weekends are those who have been admitted on a Friday. In these circumstances there can seem an unwarranted delay in 'getting the ball rolling'. This issue is, of course, addressed when the need is most urgent: that is, when patients are first admitted and require a swallowing assessment from the speech and language therapist. It is vital in these circumstances that there has been the necessary education and training

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of nursing staff so that they can supplement what is often a scarce professional resource. In the case of physiotherapy and occupational therapist the urgency will almost always be comparatively less. But to those arriving on a rehabilitation ward on a Friday it can seem something of a 'gap' in their care for rehabilitation programmes to be delayed until the following Monday.

### **4.4.5 The process of hospital discharge**

#### ***Continuity of care: a gold standard***

What became clear from many of the interviews with patients, carers and service professionals was that there is an agreed – even if rarely expressed – gold-standard hospital discharge. Certainly to patients and carers, continuity of care can mean some very simple things – at least, simple in concept even if difficult in practice. What patients often said when interviewed before discharge was that they hoped to meet (and see and talk to) the staff who were going to be working with them when they got home. They hoped that these staff would come in to see them – even if it was only once and briefly – and also meet the staff who had been treating them in hospital. Similarly, the hope was that when they went home they could be taken home by a member of hospital staff (whether nurse, therapist or rehabilitation assistant) and almost literally handed over to whoever was going to be providing treatment, care and support at home. This combination of inreach and outreach was rare in the cases of patients recruited to this study. One important difference in terms of inreach was between South Tyneside and the other two localities. The difference was the location of the Community Stroke Team on the Stroke Rehabilitation Unit in South Tyneside. This meant that those patients who would be receiving continuing physiotherapy or occupational therapy support once they got home did have the opportunity to meet the therapists concerned. They were on the ward and, however briefly, could (and did) meet patients before they were discharged. Although a combination of outreach and inreach was generally regarded as the ideal it was said to be difficult to achieve in practice because of pressure of time upon already stretched staff. In the case of South Tyneside, according to one interviewee,

*...sometimes all we've got time to do – for example two who are going out this afternoon – is go and say 'hello, we're the Community Stroke Team, we'll be seeing you from now on, this is our folder with our leaflet in it and this is your first appointment. Then they don't meet us until 2 or 3 days later or whatever.'*

*Q: But they've got a face and a name?*

*A: Yes, even when we don't get to see them [before discharge] I've had people say, 'oh, I've seen you up on the ward'. So at least they know who we are... But yes, the ideal would be to do the last [occupational therapy] or physiotherapy session in the unit as a joint session with the unit [occupational therapist] or physio. And then if appropriate, if it was a complex case, they would then come out and do the first visit at home with us. That would be the ideal – if we had time!*

Occasionally this sort of joint session was possible, but it was unusual. As it was, merely by virtue of their co-location, the Community Stroke Team were fully conversant with the treatment and therapy that the patient had received on the unit and elsewhere in hospital. Given the small size of the team and the volume of work it was widely thought to be unlikely that they would be

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able to act in this way if they were not co-located on the unit. As one senior manager in the Acute Trust argued, 'we see here [on the unit] as the best place exactly for that reason'.

### ***The importance of language: transfer not discharge***

It is worth noting that elsewhere along the pathway of care – pathway here being used in a general sense – the language is not of discharge but of transfer. This is the case when someone is transferred from the ambulance service to A&E, from A&E to medical assessment unit or general medical ward, and from there to a Stroke Rehabilitation Unit. There was general agreement among interviewees across the three fieldwork sites that the word discharge is heavy with connotations – as in its dictionary definition – of 'letting go', releasing from a 'duty, commitment or period of confinement', or even of 'dismissal or ejection'. Hence the widespread preference among many service professionals to speak again of transfer; here with its lighter, or softer, connotations of – literally – handover.

One of the consultant physicians we interviewed remarked that 'however you term it – "transfer of care" or "transfer of responsibility" – people always know that they are leaving hospital and its always a frightening time for people, and its always a bit daunting'. Asked what could be done to make it less daunting he replied that the way in which people are told about their imminent discharge could be improved. Apart from the language 'the actual time for the patient seems to come on fairly quickly and within 2 or 3 days it can be from "we are going to arrange a home visit" to "you're going home". And that's not a great length of time to get used to that.' One solution, it was suggested, might be to say more clearly to patients and families 2 or 3 weeks earlier that 'this is what we are aiming towards and this is when we are expecting you to go home'.

However carefully this is done the time of discharge or transfer will, according to one senior service manager, inevitably be difficult for many: 'I know they feel bereft on discharge because it's very intense. When you have got somebody on a Stroke Rehabilitation Unit they live and breathe their rehabilitation 24 hours a day, 7 days a week...and then they go home, the rehabilitation will be continuing but it won't be as intensive and it's very difficult for them to adjust to that'. She recognised that it was 'a big shock for the patient and their family; there is a hell of a difference sitting in a hospital ward, sitting in that security – even though nobody enjoys hospital – and actually going back home and sitting in your own armchair'. And as one therapist remarked 'I think in the end it's always such a big shock if somebody comes home with lots of problems'.

Interestingly, the 2004 Sentinel Audit notes that 'Effective longer term management of patients after discharge from hospital is critical as patients can continue to benefit from rehabilitation and help with reintegration for a prolonged period after stroke' (Royal College of Physicians, 2004, p.20). But, the report continues, 'the objective should be to transfer the care of stroke patients from hospital to community and not to "discharge".' (ibid)

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### ***The importance of process, not a single event***

Acknowledging that discharge can seem a 'big bad word' one of the therapists within the South Tyneside Stroke Rehabilitation Unit said: 'it just doesn't start 2 days before they are due to leave hospital and it doesn't end when they go home, it ends after a period of time'. This is an important point: seeing discharge as a process and as something that happens over a period of time rather than as a single event occurring at a particular point in time; that is, a process taking place for an extended period either side of the single event of someone physically leaving hospital. Another important point made by the same therapist was that 'it shouldn't be something that just happens to a person, they should feel part of that'. In addition 'close liaison' between hospital staff and colleagues in the community is of paramount importance:

*Making sure there is a good handover of information...as well as referral to appropriate agencies: making sure that they get referred to the Community Stroke Team and hopefully that a member of that team will be able to go and see them before they go off the ward, so that they know that they are not going to be on their own and that everything is not going to stop when they get home.*

*Q: In other words, a sense of going out with them, not just handing them over?*

*A: That's right – having a contact, knowing a face.*

One problem that sometimes occurred in South Tyneside was that hospital discharge was delayed because patients were waiting for home visits. This was due to a limited occupational-therapy resource (with one full-time member of staff). Such under-staffing also affected the abilities to build patient confidence and skills before a home visit. Such skills, it was argued, need to be practiced daily: 'once a week you get less of a carry over and skill development'.

### ***The importance of good communication***

For one of the patients and their carer in South Tyneside there was some confusion and problems over aspects of the planned discharge. The main problem was getting a stairlift. A lesser associated problem was with a 24-hour (overnight) home visit. The latter had been discussed as, and understood to be, a formal assessment period. Both patient and carer were, therefore, surprised at the lack of assessment: 'The thing I was surprised at was I was supposed to be assessed. But no one came...I was going out for assessment and I thought somebody would be there to see what I needed and what I didn't need'. The expectation was that this assessment would reveal, for example, the absence of grab rails in a toilet and the need for a wheelchair ramp at the back door. Moreover, the expectation was that these requirements would not only be discussed with the patient and carer but appropriate measurements taken. As it was, these were discussed after the visit and many of the necessary adaptations were scheduled to be done in the next few days before discharge. This meant they would be done without the patient being present but would be supervised by his carer: 'Which', according to the patient, 'doesn't seem a very satisfactory way of doing it. I would have liked to have been there myself. I would have liked to have discussed it with someone'. This, he thought, was the whole point of the home visit. There was also a continuing concern about the adaptations which couldn't be done

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quickly – notably the portable ramp to get the wheelchair in and out of the house.

Both patient and carer also believed that a stairlift was needed before going home: 'I wouldn't have got home if it hadn't been in, they wouldn't have let me go'. The likelihood is that this was a straightforward misunderstanding. Knowing the difficulties and delays in getting stairlifts fitted, staff do not stipulate that fitting a stairlift is a prerequisite of a 24-hour home visit. The normal expectation is that even if a stairlift is a long-term requirement home visits will be made without them and with patients and carers therefore coping with other arrangements – typically having a bed downstairs, and, where there is no downstairs toilet, having a commode. Before looking at the problem of obtaining a stairlift it is worth mentioning the other problem that occurred. This was that the carer who was coming on the evening of the home visit to help put the patient to bed was quite late. By the time he arrived the patient's carer had struggled to put the patient to bed. Both were 'shattered' by the time they had managed this. The same carer arrived on time the following morning to help the patient get up. He had been late the previous evening because his car had broken down in very bad weather.

As regards the stairlift, the carer had contacted social services and been told it would be some time – several months – before a stairlift could be fitted, and no possibility of doing so in time for the overnight stay. Believing it to be essential, she contacted a private firm who fitted a stairlift within 3 days of her enquiry – and before the home visit. It did, however, mean paying a year's rental. It is worth quoting in full this carer's views about this experience:

*When it was this stairlift carry-on I kept saying to [social services] 'I need a stairlift'. I said 'I can't really afford to just fork out £2000 to £3000 overnight to just go and have this done'... So I go through this department, I go through that department. I mean one day I must have made nearly ten phone calls trying to get to this one. This man said 'right, I'll do an assessment over the phone'. I said 'great'. So he did this assessment over the phone, he said 'right, you probably qualify, but it has now got to go to this other department and then it's got to go to the finance department, then they put it out to tender and all these people would have to come to your house to do estimates before they say which firm they are going to give the job to'. So I said, 'my husband is coming for an overnight stay next Thursday so what am I supposed to do?'. They said 'well you have got the option of bringing a bed downstairs and having a commode'. I said 'which I don't want, he doesn't want, apart from anything else how can you be doing an assessment of how he is going to cope afterwards if you are just going to do a makeshift thing?'. So at the finish I rang a firm up on the Monday said I wanted something done this week, they came and measured on the Tuesday, he came and put it in on the Wednesday. I was able to do this, but you talk to a woman whose husband is 80 and she is 79 or 80, how the hell was she going to cope?*

She then asked about being kept on the council's waiting list for a stairlift:

*'Is there anything stopping me renting one and then when my name comes up you put one in for me?'. The reply was: 'Well that's left to finance, I don't know how they will be if they come to fit one in and say 'oh but you have already got one.'*

*Q: So are you still on the list for getting one from the council?*

*A: They are still saying 'well we don't know what happens in a case like this, we haven't really come across this sort of case before.'*

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It is important to reiterate two points. First, that such problems are in part due to straightforward misunderstandings about expectations. These in turn can be partly explained by some shortcomings in communication: in this case about the 'necessity' of a stairlift and about what would happen on the home visit. Such reported misunderstandings do not necessarily indicate that staff have been remiss either in withholding information or in giving misleading or ambiguous information. Part of the problem is the sheer informality with which information is given – in this case in South Tyneside, but also the case in the other two study localities; patients and carers typically will not be given a letter spelling out purpose, duration and content of, say, a home visit. Instead, this will be discussed as part of the normal discourse on the ward: and it will be done this way not just as a means of avoiding undue bureaucracy – when, typically administrative support is at a premium – but because this is part of communicating with patients not just informing them. The second point to reiterate and underline is that descriptions of problems encountered invariably in South Tyneside (and usually in the other localities) were prefaced by, or concluded by, statements of general approbation and praise. A good example of this is the following account from another carer in South Tyneside, once again recalling problems associated with obtaining a stairlift. Before detailing the recounted problem let us quote the concluding comment: 'That would be my one big complaint about what's happening. Apart from that everything has been really good so far, really good'. Part of what was said to be really good was the delivery and fitting of aids and adaptations – handrails, trolley, bath lift – 'done within 2 days'. However, said the carer:

*I think at this point the only thing I can say about not being seamless was that when my mother came out she was advised that she needed a stairlift. And at this point I rang the social services, spoke to two people, was assured that a file would be opened, my mother would be visited by the assessor and they would ring me back and confirm all of this. They never rang back, I rang them and couldn't get hold of anyone – on holiday, etc., the usual story. And then eventually I contacted someone else who told me that the file had not been opened, nothing had been done; and this was 10 days later. And she rang me back 14 hours later and said a file had now been opened and someone would now be in contact. So here's a case of an old lady who's very bad on her feet and who needs a stairlift and after 2 weeks of trying to get something done nothing had been done, nothing has been done. That would be my biggest complaint because there's not even an assessment... I thought that was a bit naughty. So my mother after 5 days is now, with help, going up and down the stairs. But without the stairlift it means that when I'm not here that effectively has she has to sit upstairs until the carer comes, then when the carer comes at say 6 o'clock she then has to go upstairs and be upstairs until 8 the next morning. And we are quite prepared to pay if necessary, pay for part of it. But that's not the point, the point is that nothing was done.*

It is important to make the point – however apparently self-evident – that continuity of care is inherently easier when the care takes place in one location (organisational and geographical) and in respect of one episode. When, as is inevitably the case with hospital discharge, it takes place in several locations (or over several episodes) difficulties mount – even if there is a certain predictability to these difficulties where the patient is travelling along a known care pathway; in this case for stroke but equally for other conditions.

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In Lancashire the one of example perceived difficulties associated with discharge planning from the community hospitals was in relation to a patient assessed as having relatively little rehabilitation potential. A relative described their experience as follows:

*They [the community hospital] thought my Mum should go, the best place for my Mum on a nursing point of view would be a home, and as I suggested we were talking about quality of life and people having their own decisions because my mother wanted to go back to her flat... If it was up to them my mother should have gone into a nursing home [whereas] I would like to try and get my mother fit enough so she can use a stairlift so she can go back to her own home; so she has got her independence, but she is also being looked after.*

The perceived lack of information about choices in terms of support meant that on the basis of their own knowledge this family obtained Direct Payments to employ carers at home in order, as one relative said, to be 'more in control' of their mother's care. This relative thought the support, understanding and communication received from professionals was limited. For example:

*I think she was [seen as] bed blocking in the end because she kept getting infections [the family saw this as being because nursing staff were too busy to give patients proper baths and provide bed pans when they were needed]. But because we had to get the package together and employ the carers it was a long process... Now, for instance, my mother has been let out before this is set up even now. I have only just got a bank account number. The way the payroll exists, I haven't had payment yet, so if I wasn't able to negotiate an overdraft, if I wasn't able to have money in the bank to pay the carers, my mother couldn't have come home yet and it would have been another 6 weeks or 4 weeks. So the facility [of Direct Payments] is there but they don't tell people about it because it is a lot of hassle.*

In this one instance the family felt that they had been 'left to it' by social services. As is the case for therapy services in the NHS, this illustrates the variability of social services across the area teams. Although several NHS staff and managers argued that the lack of social workers attached to the community hospitals made things difficult in terms of arranging discharge, this was not an issue for patients and families. The only example of perceived discontinuity was for the patient discharged to intermediate care – where, as was the case for transfers from Blackpool Victoria to the community hospitals: 'I didn't know until the day and the wife didn't know either. They don't like telling you much, it's on a need-to-know basis'. The other patients and families did not perceive any major difficulties and thought they had been given appropriate notice of discharge and so adequate time to prepare at home. They had also been effectively linked into Social Services Benefits Advice, the Stroke Association, Age Concern and other relevant agencies for additional support and were easily able to contact a named social worker if necessary. Social workers were also said to be responsive in addressing problems (e.g. the need to change agency home carers, or access day care) if those emerged.

### **The importance of continuity of care 'off the stroke pathway'**

Pathways will differ in their detail, formality and design – in terms of organisational and professional responsibilities. What is inherently much more unpredictable and therefore much more problematic is the care that might be required, as it were, 'off-pathway' – the care that a person with a stroke receives when treated for illnesses unrelated to their stroke. This can occur

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both in hospital (whether acute or rehabilitation) and after discharge. In this study there were several instances of stroke care being 'interrupted' by the need for the general medical and nursing care associated with unrelated illnesses. Almost inevitably some older people in hospital will acquire chest infections or urinary-tract infections or other illnesses which affect and may temporarily halt their rehabilitation and recovery. What matters to the patients and carers – apart from obviously successful and speedy treatment – is that the stroke goals and programmes are not lost sight of. This is less problematic when the care is within the same hospital as part of the same admission – and much less problematic when it can take place on the same specialist stroke unit. It is much more problematic when it takes place as a separate episode outside the specialist unit. This is the experience of two of the patients in this study in South Tyneside (and of others in the other sites). In one case treatment for a condition unrelated to the patient's stroke was given at a hospital at a different locality. Here the problem was simply one of the condition preventing the patient taking part in post-discharge rehabilitation. Physiotherapy from the Community Stroke Team was offered but not taken up. Progress thus slowed and there was doubt about whether the community physiotherapy service would be picked up again some weeks later. In a sense this was an understandable self-imposed discontinuity of care. All that is required in these circumstances is some reassurance that when people are ready they can request the resumption of the rehabilitation programme: that is, reassurance that it's not stopped just because they have exceeded the time limit that they understood to have been originally imposed.

The other case in South Tyneside involved a patient who was readmitted to hospital for an infection, once again unrelated to the stroke that had led to the original admission. Here, as well as some serious concerns about the quality of the care on the medical ward, there was a feeling of disruption to the stroke recovery and rehabilitation due to being treated – albeit in the same hospital – as an entirely new case. Patients and carers generally accept the inevitability of being seen in this way. But they also voice what seem to be reasonable concerns about the absence of some sort of collective, organisational memory. Or, put more specifically, the sort of care which begins, in effect, with staff saying: 'Hello Mr X, you were with us only recently on the stroke rehab unit weren't you. Now we've looked at your notes and we've discussed with colleagues where you're up to with your present programme of rehabilitation. We're going to have to sort out your current problem but we're also going to do whatever possible to make sure that we maintain your stroke recovery and rehabilitation'. What is possible may in practice be very little and not for some time. But at least the message communicated to patients and carers is one of some continuity – continuity as the same person coming back to the same hospital, although now for something else, with the same needs for joined-up treatment, rehabilitation and care.

There is, of course, an inevitable limit to what can be done to help some patients. Most obviously these are limits to available capacity and resources. South Tyneside is among the minority of localities with a Community Stroke Team (see Royal College of Physicians, 2004), but this team is relatively small and has a limited capacity. South Tyneside is also among the minority – an even smaller minority of localities – of those with clinical psychology input. Even more impressive is the way in which this limited resource (less than full-



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time) is stretched to cover patients first seen in hospital when they've been discharged. Although there is as yet no dedicated clinical psychology support to the Community Stroke Team this, it ought to be said, is due as much to problems of recruiting a limited resource as to making available local funding. Only one of the recruited patients in South Tyneside had significant depression – and this was in hospital as well as after discharge. Although aware of the help available from clinical psychologists – though understandably unaware that this remains a rarity in most local stroke services – the patient said she hadn't wanted to see the clinical psychologist 'because I just didn't feel up to anything: I get very depressed'. And yes, she said, simply and perceptively, 'I know it's like Catch 22. She came round to see me and unfortunately when she did I was in a very depressed state'.

Other experiences of care at and after the point of hospital discharge which patients and carers recounted comprise two groups: those relating to the provision of aids and adaptations; and those relating to home carers. As regards aids and adaptations, and notwithstanding the above comments, there was widespread praise for the speed and efficiency with which the occupational therapists assessed and arranged for all the aids and adaptations. As one ex-patient said: 'The chaps came out and put a rail up the stairs – fine. The toilet seat arrived. So that part, fine. They put a grab rail at the back door. And they heightened my chair. That was excellent. So I'm level – it's marvellous, it's really good'. The general view about home carers was similarly positive. In only two cases were any problems mentioned. The carer of one patient referred to the problem of different independent-sector providers having contracts to provide the four-times-daily personal care and twice-weekly practical care. This, allied to changes in individual carers, made it 'a bit bewildering'. One other patient and their carer referred to having been introduced to care workers in hospital 'And one of the girls said "I'll be coming in the morning and the other will be coming at night". But they didn't show up at home'. There was some uncertainty about whether the same carers would come each day: 'I think it's a different firm; Monday to Friday are one sort of firm, but I think Saturday and Sunday is somebody different'. And as regards timing, 'The only problem is you don't know when they're coming. You don't know what time they're coming in the morning and you don't know what time they're coming in the evening'. It was, however, acknowledged to be difficult for carers to be able to say exactly when they were coming given their workload with other users and, overall, 'They've been very good'.

### ***Seamless handover: passing the baton***

In Darlington Memorial Hospital one patient was full of praise for the arrangements made for her hospital discharge and the way in which it took place. First, she was involved in discussions about when discharge would be appropriate. A week before the proposed discharge date the occupational therapist on ward 41 discussed at length the discharge procedures and care needs at home. The occupational therapist arranged to do an environmental visit prior to discharge and for social services to visit the patient to discuss care needs. As the agreed date approached the patient was interviewed in the ward by a social services care manager:

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*'we got together in the day room on our own and talked about what my care plan was going to be. She suggested things, gave me the options on the meals and everything; but it was up to me to decide what I would like... I just felt I needed a carer for half an hour a day'.*

*Q: But if you'd said, oh I'd like one twice a day?*

*A: Yes, I could have had it from whatever, like twice or three times a day.*

*Q: And if you found you wanted more?*

*A: I could have it.*

*Q: You could just ask for it?*

*A: That's right.*

The care manager arranged for a carer to visit every morning, 7 days a week for half an hour. It was agreed that she would provide basic practical care 'as indicated by the patient' – such as laundry, hoovering and emptying the commode – as well as general support. Thus 'she doesn't wash and dress me or anything like that'. But she did watch to see that the patient could get in and out of the bath safely; and similarly 'go up and down the stairs – it was just to watch me'. On the day of discharge the patient was accompanied home by the occupational therapist from ward 41 together with two rehabilitation assistants. Ward staff also informed friends of the patient (who had no family carers) and they were present on her arrival home from hospital. Together the staff, patient and friends confirmed that the house was safe and agreed what additional equipment was needed. The occupational therapist returned the following day with this equipment including a wheelchair seat, shower board, trolley and a perching stool. A tangible sense of being 'handed over' was a great source of reassurance to the patient: 'it was very good'. This was reinforced by her referral by the occupational therapist to the Community Rehabilitation Team for twice-weekly physiotherapy and occupational-therapy support. The community physiotherapist, according to the patient, 'doesn't rush, just takes her time and goes through my exercises; and does exactly what I did in hospital. If I'm not doing it right to put me right – in a loving manner. I am just getting the same treatment as I was getting in the hospital'.

This latter comment is an extremely important one in the context of this study. Patients' experience of continuity of care was defined essentially by the perception that wherever there was a transition in care – from ward to ward, from one member of staff to another and especially from hospital to home – that this was seen and felt as a smooth handover and seamless transfer. Handover here means something both particular and special in the context of continuity of care. Handover literally means being taken by a member of staff in one unit and being given directly into the care of another member (or members) of staff in another unit. An apt metaphor would be the one from athletics of handing over the baton in a relay race. The crucial elements here are passing the baton smoothly from hand to hand: it cannot be thrown, it cannot be left lying on the ground to be picked up and it certainly cannot be dropped. The other crucial element for the patient is that such a transfer not rushed and is personal: that is, that they are fully informed, with, as far as possible, any queries or concerns addressed and allayed.

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Asked in ward 41 about her imminent discharge another of the patients remarked upon the occupational therapist having contacted her family and having been to her house for an environmental visit:

*...that has all been seen to. I thought it was wonderful...[the occupational therapist] won't let you go unless you are sure that you will be able to cope, which is the main thing... I have also got aftercare at home: I've got someone coming in, it would be about 4 times a day. At my age you have to be sure that there is going to be somebody there.*

*Q: And have you been asked what you wanted and offered what you asked for?*

*A: Yes it would be all sorted out today...it's all happening here. I was surprised that they went out to the bungalow, but they won't let you go unless you are alright to go so it's a good thing I think, very good.*

Interviewed 2 weeks after her discharge the same patient recalled, with pleasure, the process of discharge itself. Here – as with the other patient referred to above – she was accompanied home by an occupational therapist and a nursing assistant. She was met at home by her daughter and also by the independent-sector carer arranged for her by social services: 'they were really helpful'. This was a literal handover, with the ward-based staff (occupational therapist and rehab assistant) able to describe to the daughter and carer the patient's treatment and rehabilitation in hospital and discuss what her needs now were – needs specifically in terms of how they could best help by encouraging and supporting the patient walking and transferring.

Unfortunately this well-arranged discharge was marred, albeit briefly, by the patient's experience with her first carer: 'She was a bit new. She didn't seem to know much at all. She didn't really like the job'. On the first morning 'she was supposed to be here at 8.00 and it was 9.20 when she rolled up. So of course I was getting a bit worked up by that time. I wasn't feeling too well and I could easily have sat down and cried about it all. I did get myself a bit upset. I felt I had gone back a bit through that. It was a bit emotional...a couple of days I was quite depressed, but I did get over it'.

This underlines the importance of a smooth handover of care at a time when patients feel vulnerable. As several staff commented, after many weeks of inpatient treatment, rehabilitation and care, patients understandably become accustomed to 24-hour care. They may be critical of some aspects of this hospital care but they know – even if not consciously acknowledged – that they have the safety net of around-the-clock hospital monitoring and care. Especially for people living alone – as was the case for all the recruited patients in Darlington – and especially for people who have experienced the trauma of a stroke, discharge home after a long period is invariably, therefore, a time when they feel extremely vulnerable. They may be longing to leave hospital but without exception those being discharged wanted to know that appropriate rehabilitation, care and support would not be turned off at the point of discharge. An important part of continuing recovery is the knowledge that there will be such continuity of care and support after hospital discharge.

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### **4.4.6 Post-discharge care and support**

In Lancashire (Fylde and Wyre), health-service contacts with stroke patients continued as appropriate via day hospital (at the relevant community hospitals) or outpatient review clinics either at the community hospitals or Blackpool Victoria. In addition, allied health professionals based at the community hospitals potentially referred stroke patients to the speech-and-language-therapy day service at Southshore Hospital. Once the patient's period attending the NHS day hospital is complete, it is up to social services to refer, either on the initiative of the social worker or following a patient's or family's own request, to an alternative local-authority-funded day-care service. Importantly, those services are not always suitable – for example, because of limited numbers of transport places for wheelchair users. This lack of day care was growing as an issue for patients and families towards the end of our fieldwork period because day-hospital provision at the community hospitals was being discontinued (see below). Another issue raised by staff specifically in relation to outpatients was that, as noted above, not all patients transferred to the community hospitals continued to see a designated Stroke Consultant. This meant that although

*...when they come into the acute stroke ward they are under [a stroke consultant] once they are moved to the community that isn't the case, there are a number of different consultants. So when they come in for an outpatients' appointment it would be under a different consultant.*

GPs are involved with patients post-discharge from the community hospitals, specifically for referral back to Blackpool Victoria for outpatient clinics, or for ongoing physiotherapy from the NHS community sector (for Fylde and Wyre GPs this is to relevant community hospitals of Rossall and Clifton), intermediate care (e.g. Blackpool GPs can refer patients back to the Blackpool social services intermediate-care facility known as the ARC) or Kirkham prison. They are also potentially involved with community pharmacists in terms of patients' medication and ongoing health checks.

Although the majority of patients said that arrangements for outpatient attendance at the community hospitals had worked smoothly, one family's experience raises the general issue of what are often seen as loose links between primary and secondary care following discharge. As the daughter commented when asked about outpatient attendance:

*She [mother] goes to have her blood taken. [At Clifton?] Yes, but they were sending her to Victoria. And the second day out of hospital, knowing she had had a bowel infection, she was made to wait 4 hours, taken in an ambulance and brought back. So she got up at 10.00 because we weren't sure what time the ambulance was coming and they brought her back at 3.00. So that was a good day out for somebody who had just come out of hospital. [And that was for a blood test?] Yes. [And the district nurse couldn't take it?] Well apparently that happens in other areas but here... Well sometimes you get sick of fighting so you let things go over your head ... You chose the ones you can win and you chose the ones you can't.*

In relation to follow-up by GPs too, only one patient had experienced what he regarded as difficulties. On discharge from intermediate care, the patient concerned had received medications and arrangements for repeat prescriptions were working smoothly, but he felt 'you are shut off once you are discharged' and reliant on GPs to review medication, progress, etc. He

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said of his GP: 'She has never been near...and to think we have been with them a long time'. The remaining patients, however, said their experience had been very good. One had seen her GP relatively soon after discharge: 'He gave me a check over' and had made a further appointment for a blood test and general monitoring in a month's time. Another had seen his GP and was now content with the 'very efficient' arrangements for repeat prescriptions and medication monitoring through the community pharmacist – 'they would even deliver'.

Another type of GP contact highlighted was in relation to the small number of patients discharged home directly from Blackpool Victoria without subsequent rehabilitation. For example:

*We had one the other day that I've got to follow up. And it was a GP referral into our service as outpatient, saying that this person had gone into the Vic and he was having extreme difficulty with mobility. Now is it because he wanted to go home? We don't know. Or is it that he just got discharged home because he was actually on his feet, you know albeit just chair? I don't know...looking at it on paper he is youngish, I think 50s, 60s, why had he gone home? You know he should be for a rehab bed at Clifton or even one of the other rehab hospitals... It's not too many [cases like this] we get but we do get them that they have gone home, then they start failing or... it hits them that they have got a problem and they go to their GP. So we don't know why.*

This example serves to highlight the difficulties associated with what several NHS interviewees described as the emphasis on the 'linear' care pathway (i.e. acute to community rehabilitation beds) through the health system locally, with a perceived lack of mechanisms to track patients that do not take the 'standard' route and who may therefore not be known to the stroke specialist nurse. As several NHS interviewees argued, such a situation means that patients potentially receive a very different service compared with patients who the stroke specialist nurse is made aware of and manages to route through ward 20.

In one telling comment this patient also observed that intermediate care 'was really helpful... But there are two lots of people getting funding to do the same thing. They should come together in their approach.' The more intensive rehabilitation provided in intermediate care meant for this patient that:

*I can see the end in sight now and get home and finish. [It has been a long time hasn't it?] Too long ... you get sort of acclimatised – no that's not the word, I don't know what you would call it really, institutionalised should I say and it's not for me at all. It might be for some people but it isn't for me.*

In a later interview he made it clear how the delimited time (of 6 weeks) in intermediate care provided a definite goal and added motivation to get the most out of the service available because it was finite:

*Oh yes I can see the outcome now. Another 2 weeks and I'm gone. Because I thought I'd never bloody get out of Clifton you know... I don't know what it is with this [stroke] they don't seem to want to let you go, none of them.*

Elsewhere patients and families commented on the length stay in the community hospitals as not conducive to successful rehabilitation. Two such comments were: 'I am just impatient to get home and get about'; 'About 13 weeks I think nearly 14 [I was in Clifton] I'd had enough. I am very glad to be home'.

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### **Aids and adaptations**

We have referred above to some of the problems with aids and adaptations experienced by patients and their carers in South Tyneside around the time of their hospital discharge. These were problems in a locality with a unitary local authority responsible for both social services and housing. They were also, it is important to stress, problems being addressed urgently by social services managers. In Darlington, as indicated below, there were similar problems for one of the recruited patients. Here, however, as in Lancashire, there needs to be good joint working between separate social services authorities and (for non-Darlington residents discharged from ward 41 at Darlington Memorial Hospital) neighbouring District Councils as housing authorities.

In the case of Lancashire patients and families experiences with the delivery and fitting of equipment and home adaptations varied according to the route taken through the health and social care system. All of the patients that went through Clifton Hospital received their made-to-measure wheelchair while they were in hospital, whereas at Rossall the patient concerned was told it would be 12 weeks after discharge before her wheelchair could be delivered. By contrast, however, she experienced no delays in the provision of other equipment and home adaptations (zimmer frame, hand grabs, stair rails, bathroom adaptations). In the latter respect, patients leaving Clifton Hospital did recall some problems. One relative described the Clifton experience as follows:

*No we had nothing, we had no equipment, we had no help at all. We had no rails in the toilet and we didn't have any help at all really, apart from his wheelchair. [So how long did it take to sort out?] Oh not that long really. I just had to keep ringing occupational therapy and saying 'This won't do'.*

Although things were sorted out relatively quickly, continuity of care for this patient was compromised by the appropriate equipment not being in place. Such cases seemed bewildering to patients and carers alike after they had been in hospital for several months with, in their view, ample time for arrangements to be made. A second issue for this family was that Equipment Services were unable to give them a firm time for delivery of their bath hoist. This meant that on the first delivery attempt no one was at home, and they then had to wait in until the hoist arrived several days later.

Once again, the experience of the one patient in intermediate care was different. Although it took several weeks for bathroom adaptations, stair rails, access ramps and lift at the outside door to be installed, and 'I am housebound until I have got that', the patient said he was clearly told about the possible delays. Moreover, he 'could have stayed in [intermediate care] until they got [the adaptations] done'. It was simply his choice that he 'thought "No way, I'll come home". At least I'm here. I can gee them up that way can't I?'. Despite acceptance of the delays, however, the patient commented on the several different contractors employed to carry out the necessary work. For example, he had one visit from a contractor simply to install an electric socket but had to wait for another to receive the equipment itself. He also said that although expensive bathroom adaptations (including a new walk-in shower) had been completed, it was due to be another two weeks before his bath seat was delivered. As he said: 'You would think they would co-ordinate [the delivery of different pieces of equipment] better'.

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Significantly, this patient also commented on the different equipment and adaptation support that would have been available if he had been discharged straight from the community hospital. 'Well all they were talking was a bed downstairs plus a commode'. He thought that staff at the community hospital had simply underestimated his potential for achieving a more 'normal' life long term.

In Darlington the same patient who was so complimentary about the general level of community-based care and support – and the co-ordination between the agencies and carers concerned – did voice one reservation. This was that more than 2 months after discharge she hadn't been provided with a ramp at her front door. 'The council', she said, 'are supposed to do that' and had been asked to do so. But 'at the moment they have to lower me down [but] you are not supposed to do that'. Although a temporary ramp had been suggested she was, she said, 'not really all that happy about [it]'. As well as the ramp she had also been told when she came home that she should 'have a handle next to the toilet just to hold on to, but they haven't been and done that yet... I just hold on to the windowsill and that's tiled you see, so it's flat; but I have to make sure my hands are dry'. With a combination of resignation, understanding and patience which typified the majority of patients and carers interviewed in this study she concluded by saying that although she and her daughter 'are going to try and push the council...I know it's the budget and all that'.

### **Shortage of community therapy**

We have referred elsewhere in this report to the problems associated with shortages of staff to provide even a generic let alone a specialist community rehabilitation service for people who have had a stroke. In Darlington there were concerns about the lack of a specialist Community Stroke Team and about the severe shortage of, especially, clinical-psychology and speech-and-language-therapy resources to generic community services. In South Tyneside, although there was a highly regarded Community Stroke Team it was widely acknowledged to be similarly short-staffed in terms of speech and language therapy and more generally under-resourced in terms of nursing, occupational therapy, physiotherapy and clinical psychology.

In Lancashire one of the main issues was lack of community therapy – made worse by closure of the day hospitals towards the end of the fieldwork period. Only one patient in the study was able to attend the day hospital (at Rossall), where she described the games and exercises as 'very good' both socially and in terms of maintaining motivation for continued rehabilitation. As she said: 'It kept you going', but

*...it [day hospital] finished the week before last because they are closing, closing the day service. They are closing about three hospitals. They are short of staff and they are deploying the staff on to the wards. Not only Rossall, at Southshore, Clifton and somewhere else as well... They are supposed to be opening again January, but I can't see it. If they can't get staff now for the hospital, they are not going to get them in January are they?*

For this patient the subsequent transition to social services-funded day services (which provides social activities but not therapies) had worked quite smoothly and was not an issue because she had recovered well so no longer required therapy input. Rossall Hospital had contacted social services when

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they knew the day care at the hospital was finishing, and social services had arranged for her to attend a day centre in Bispham at a cost of £3.20/week. The only issue for her was that 'They [social services day services] are very busy with all these hospitals closing', and she observed that not all of her fellow patients had successfully 'got into' alternative provision.

For the other patients in the study who did not yet feel fully rehabilitated, the closure of the day hospitals was more of an issue because of the lack of therapy services in the community. One was simply not given the opportunity to attend because 'They've closed the day hospital at Clifton now' – a fact he and his family thought was problematic in that there was now nowhere for them to go for advice about continued rehabilitation – even if this was low-level maintenance involving primarily self care. Another Clifton patient, who had the perceived added difficulty described above of having to find things out for herself associated with taking on Direct Payments, had also been discharged with no advice regarding day services. She said:

*I won't go to outpatients, but I am going to join a stroke club [suggested by chance by one of her carers whose own relative coincidentally had attended the club following a stroke]... They have entertainment and sometimes they just chat and have days out.*

As already noted, the recruited patient who was discharged via intermediate care had received advice regarding day services, but had been unable to attend because of a lack of transport places for wheelchair users to get to the Centre. Importantly, from his point of view intermediate care had a number of benefits, particularly given the absence of the 'intensive rehabilitation' expected at Clifton, which the hospital had not been able to deliver due to a shortage of allied health professionals. In this context, intermediate care provided a second chance for more one-on-one support and rekindled motivation to progress further and/or to accept disability having had a 'proper' attempt at rehabilitation. This is perhaps an argument for better information to patients earlier in the care process (i.e. about the level and intensity of extended rehabilitation that they should expect). As one service manager pointed out in relation both to the Gloucester Unit at Clifton and Rossall Hospital: 'Probably one of the biggest problems we have is patients get told they are coming to us for intensive rehab and their ideas of intensive rehab are totally different to what a physio's idea of intensive rehab is...it can be difficult.'

Another issue in terms of post-discharge follow-up was the lack of available community physiotherapy. In this context, the patient discharged via intermediate care encountered problems due to the complex geography of health and social services locally. He had wanted to go back to the (Blackpool social services-funded) ARC intermediate-care facility for a reassessment and additional exercises to continue with at home. The ARC was willing to reassess him, but the referral had to go through the patient's GP – and as a Fylde GP she could only refer to Rossall Hospital where there were no physiotherapists available without going on a long waiting list. The patient was now in a situation where, 'I said we'll go for a private one [physiotherapist] because I am just static now. I am not getting forward like I should be. I should be progressing and I'm not'. The decision to pay privately had not solved his problem however, as 'decent physios [NHS or private] are few and far between apparently'. The same difficulty had been encountered by the patient



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discharged with Direct Payments: 'We are looking for a physio, but unfortunately we haven't been able to get hold of anybody'. Two of the patients in the study had considered bypassing the NHS system to access additional rehabilitative physiotherapy at Kirkham Prison. As one said: 'The wife wanted me to go to Kirkham Prison because that is supposed to be brilliant physio there for strokes. But you have to get your doctor's [GP] approval and she just pooh poohed it'.

### ***Joined-up post-discharge care and support***

We were able to follow-up three of the patients recruited at Darlington Memorial Hospital for some time after their hospital discharge. Two of the three received continuing therapy from the same Community Rehabilitation Team – based in County Durham, not in Darlington. Both also received social care support, again arranged by Durham not Darlington Social Services. One of these recruited patients, who received community-based therapy and domiciliary support after hospital discharge, was interviewed four times after she returned home. She was extremely complimentary about both the therapy she received from the Community Rehabilitation Team and the social care support organised by County Durham Social Services. The former, she said, 'are really excellent, they really are: it's continued rehabilitation'.

*Q: It's as if you have just been handed over?*

*A: It's a continuation helping me, yes. Seeing how I have progressed and if I am doing anything wrong they will point it out to me in a loving way... The physiotherapist doesn't rush me; just takes her time and goes through my exercises and does exactly what I did in hospital. I am getting the same treatment as I was in hospital.*

*Q: As if it's the same team?*

*A: It is. It's as if it's the same team, yes.*

This physiotherapist and occupational therapist support began 2 weeks after discharge – 'but I wasn't hurt about that: I felt alright about that because I have been able to do things for myself which I needed to do' – and continued twice weekly for 6 weeks. By the end of this period the patient was walking confidently and going shopping locally by bus. She thought this period of rehabilitation was sufficient. She wanted to regain her independence not only walking unaided but returning to work on a part-time basis – which she did successfully 5 months after her hospital discharge. She was equally clear that the social care support she received was what she wanted, for as long as she wanted it. In practice this was a short period of time. She received such care for 5 weeks from the time of hospital discharge.

Interviewed three times over a period of just over 3 months after her hospital discharge the other patient said that after the initial poor experience with her first carer post-discharge (as described in the preceding section) she was 'really happy' with her subsequent carers. A change in care providers had been made by social services as soon as they had been contacted by the patient's daughter following the initial late visit. The care package, from one or other of two carers, comprised 30 minutes, four times a day, 7 days a week. Separately she also received visits twice a week for a bath, 1 hour's support each week for shopping and one for laundry and housework. She described how the carers 'wheel me into the bathroom where I wash myself;

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or if I get stuck with a zip or hooks and eyes I just give a shout and she comes and helps me. And then when I've got my clothes on, she wheels me in here and while I've been washing she gets my breakfast'.

She was full of praise for the fact that she could negotiate the times of visits: 9.30 p.m. not 8.00 p.m. was, she said, her choice for getting to bed. 'You can choose more or less your times: they ask "do you want it earlier or later?"'. The same was true for the times for having a bath. Being able to choose was something she appreciated: 'between you and your carer you can do that'. She described her carers as kind and reliable: 'they are very nice girls'. And, she said, she was very reassured to know that she could call at any time if there was a problem: 'she says "if you are worried about anything just give us a ring", so it couldn't be better than that'.

This same patient was equally complimentary about the help she received from the Community Rehabilitation Team, with the physiotherapist (or, usually, the therapy assistant) visiting three times a week. This was 'very good' not just in terms of continuing exercise but because with occupational-therapy assistance too she was finding the confidence to go out and be taken shopping.

One other aspect of her care at home which this patient remarked upon was the co-ordination between the Community Rehabilitation Team and her home carers: 'the stroke people have put a book [which] the care workers are to sign and write on...they have to walk me up and down, that's a bit of time off their half an hour...they have been told to do that as well'. 'All in all', she said, 'I find it very good really. I feel quite happy with it...when there is different departments all to do with strokes and they all seem to confer and all that, that's a great help. It really makes you feel better'.

*Q: It looks as though they are all pulling together.*

*A: Yes, definitely.*

This was one of several occasions throughout the study when patients (and their carers) remarked upon the benefits of what they themselves saw as some form of joined-up working. Typically such comments were indirect or the benefits were implicit in interviewee's comments. Indeed, as we have argued previously, the benefits of joined-up working – in terms of promoting, and representing continuity of care – are typically apparent to its recipients by its absence rather than its presence. In other words, patients more readily note and remark upon the problems caused by agencies and staff appearing not to be working together or communicating with each other – with discontinuities of care evident in care gaps, shortfalls, overlaps or delays. One other important facet of continuity of care demonstrated by this patient's experience – and widely shared by others – is that of flexibility. Continuity of care in this sense means the ability and willingness to respond and adjust to people's changing needs and preferences. It is care which is continuously sensitive, but to be properly sensitive it needs to be care which looks for changes in needs and preferences rather than merely responding to them. This, of course, is little more than the common currency of good-quality care – whether medical, nursing, therapy or social care. Finally, it is important to stress the significance which patients in this study attached to offers of continuing support (and, by extension, continuing interest and concern) beyond the point at which such support formally ends. Even if now at the level

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of 'potential' care it represents a reassuring safety net as important (even if less tangible) as a care alarm system.

### ***4.5 Summary***

In view of what appears to be a lengthy catalogue of shortcomings perceived by patients and carers at all stages of the patient journey, it is important to reiterate a caveat made at the beginning of this section. This is that overall the 18 recruited patients expressed general satisfaction with most aspects of their stroke treatment, rehabilitation and care. Indeed, many were full of praise for most aspects of their care, including a sense of continuity across the transfer from hospital to home. It is worth underlying this generally positive set of recollections for two reasons: first, because it is in such contrast with the experiences recalled by users and carers in our learning disability case study; and second, because, as we have said, people tend to express frustrations and describe perceived problems at great length, whereas they typically express praise only in brief. Unlike experiences recorded in learning disability services, stroke services were characterised by continuities of care not discontinuities of care, and in many cases much more by continuities of care.

One of the starkest contrasts between the two case studies was in the provision of information and the involvement of patients and carers: generally poor in the case of learning disability services; generally good in the case of stroke services. The latter was not just in care planning and goal setting but in discharge planning which included, for carers, being encouraged to come into hospital to learn about moving, handling and safe transfers. Information provided – both written material and videos – was generally thought to be timely and helpful. Where they were available – in South Tyneside – patient and carer groups (e.g. the adjustment group organised by the clinical psychologist) were regarded as a good opportunity to obtain and share information with 'real experts'. As might be anticipated, some concerns were expressed about transfers within hospital (i.e. between wards) and, especially, between hospitals in the geographically dispersed service system in Lancashire (Fylde and Wyre). Transfers involve a literal disruption in the flow and continuity of care and therefore to some extent can be expected to be points of perceived discontinuity, as patients change the staff and physical environment (and routines) of one ward for another. Transfers do not inherently involve discontinuity; they can as easily be a welcome transition which marks expected or actual improvement in recovery. They will be problematic where they involve a move undertaken largely for bed-management purposes (i.e. in the context of a 'red alert'). They were also problematic when, as recalled by one patient, a transfer involved being moved to the Stroke Rehabilitation Unit (in South Tyneside) on a Friday evening – only to find that he would have to wait until Monday for physiotherapy to begin. This seemed an unwarranted delay and discontinuity – and one that highlighted the apparent anomaly of therapy staff not being on duty at weekends whereas medical and nursing staff were always available. At least, they were in principle available. In practice several patients referred to one particular problem – stemming, it was almost always said, from pressures on staff caused by short staffing – which was the repeated response of 'in a minute' to calls (frequently urgent) for assistance to go to the toilet. However

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seemingly small-scale a complaint, this was cited as an illustration of the many apparently mundane ways in which the how (and when) of care is as important as the what.

Apparently simple things were similarly at the heart of what patients and carers thought to be the essence of good hospital discharge. First there must be good communication and prior information and involvement in planning for exchange and beyond. It is as important not to raise expectations – about, for example, what equipment or adaptations or other support will be available. It is important for patients and carers to be clear about who they will see post-discharge (and when and for how long and why); and conversely who they should not expect to see as a matter of routine. It is even more important that patients have an opportunity to see and speak to their post-discharge carers prior to being discharged. The ideal is a combination of inreach and outreach with staff on either side of discharge being involved in the literal handover of patients. This sort of seamless handover is akin to ‘passing the baton’ in athletics. Especially for older people who have had a stroke and who, as a result, are often physically less independent, such a sense of literal handover is an important means of lessening anxiety and feelings of vulnerability after what is often a lengthy period in hospital.

The athletics baton metaphor is a particularly apt one because patients expressed the wish not to be apparently dropped by one agency or set of professionals and have to wait to be picked up by another: and a wish, too, that care and support not be turned off once they have been formally discharged from any service. Many patients spoke of the importance (and reassurance) of knowing that they could contact services (and individual professionals) if they were concerned about their circumstances, whether a perceived lack of progress, a perceived need for tangible support or low mood and motivation. This, in effect, is continuity of latent care. Much more tangibly and much more immediately, post-discharge there were several difficulties with the provision of aids and home adaptations. Delays and difficulties at this stage are doubly frustrating for ex-patients and their families: first, because of the straightforward effect which not having steps or ramps or rails has upon someone’s ability to adjust to home living and to continue rehabilitation; second, because it seems such a marked contrast to the 24-hour care in hospital. And as such it can seem to reflect the disjunction between parts of the care system and the realisation of anxieties about being ‘dropped’ or ‘lost’ after discharge. Finally, it is important that continuity of care be seen as something much wider than what takes place only on the stroke care pathway. Patients who have their recovery or rehabilitation interrupted by, for example, another (unrelated) illness or injury need to feel that in other contexts with the health and social care system there is knowledge of and understanding of their circumstances in relation to the stroke. Continuity of care, in other words, needs to extend off the care pathway, not just along it.

## ***4.6 Conclusion***

The principal aim of this study has been to examine patients and carers’ experiences of stroke care across the patients’ journey. Although our main focus has been on the hinge point of hospital discharge – the transfer or transition from hospital to home – we have also looked at how services are

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joined-up and experienced as continuity of care prior to and subsequent to the time of discharge. We have found considerable evidence of experienced continuity. This is a marked contrast to the learning disability study in which we concluded that experience of transition for young people leaving school is mainly characterised by discontinuities. Precisely because this broad general experience was of continuity we will end with an extremely positive account from a patient in South Tyneside. Before doing so, however, we need to outline briefly some of the explanations that were given for the discontinuities that were apparent.

These explanations reflect different levels of the context within which care is planned and delivered (see Section 6). In terms of the inter-organisational context we can conclude – and in doing so concur with Derek Wanless – that a context of marked inter-organisational complexity, in terms of severe organisational turbulence and a multiplicity of overlapping organisational boundaries (and roles and remits), is one which impedes rather than promotes partnership working, the adoption of a whole-system approach and service integration. Such complexity makes joined-up working – and, by extension, a delivery of continuity of care – more difficult. On the other hand, inter-organisational simplicity (i.e. conterminosity) and relative stability are solid foundations for – but not guarantees of – such joined-up working. The evidence from this study is that services in South Tyneside prospered in just such a context of relative inter-organisational simplicity, just as they were hampered in Darlington and, even more, in Lancashire (Fylde and Wyre) by contexts of considerable inter-organisational complexity.

At the level of inter-professional working we found perceived difficulties with the composition of stroke teams. First, it was widely agreed – as spelt out in most of the guidance – that social workers are important team members, especially in the planning and management of hospital discharge. None were members of the stroke teams in any of the three case-study localities. The problem for social services is how to manage a limited resource with competing claims from other specialist teams. In Darlington and Lancashire (Blackpool Victoria Hospital) Hospital Discharge Teams were a valued resource, but they are a generic not a specialist resource. The second difficulty was the absence, except in South Tyneside, of specialist Community Stroke Teams – and even in South Tyneside this is a very small team. There was evidence of some boundary disputes and tensions (a) between specialist stroke staff in hospital anxious not to discharge patients as soon as they otherwise would if there was a specialist community resource and (b) about social services staff who had not attended ward-based MDTs reassessing patients at the point of discharge. There was a particular concern about the shortage of some staff. With the exception of South Tyneside there was no clinical psychology input to stroke services – a problem both in hospital and in the community. There was a similar dearth of speech and language therapists in the community, even as members of generic community rehabilitation teams. Finally, concerns were expressed about shortages of occupational therapists – with, often, the effect of delay in discharge because there had not been a home visit – and of physiotherapists, especially in the community. The overall conclusion was that there is much agreement that a specialist integrated stroke service which operates across the whole patient journey needs specialist expertise at the acute stage, in post-acute intensive rehabilitation, and in post-discharge community services. Self-evidently,

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however, staffing such a joined-up specialist service has major resource implications, as the stroke service plan for South Durham and Darlington well illustrated.

The pressures on staff and shortages of staff were mentioned by many of the 18 recruited patients when interviewed about their experiences. To some this seemed to lessen the amount of therapy that they had expected, to others it resulted in a prevailing 'in a minute' response to requests for assistance, whereas to others it meant having too little time to discuss their care and prospects with staff. There were some communication problems but overall patients and carers were extremely satisfied, both with the information they received and the involvement they were encouraged to have in all aspects of care planning, before and after discharge. Hospital discharge itself typically was a relatively smooth process but in only a minority of cases did it approach the notional gold standard of seamless handover – and literal handover – with staff, in a combination of inreach and outreach, working together either side of the point of discharge.

It is because the principal focus of this study has been on the point of transition from hospital to the community and home that we have concentrated on how stroke services are joined up at the end of a patient's hospital stay – prior to, at the time of, and subsequent to discharge. However, we saw one very good example in South Tyneside of how important it is that such services are well integrated from the start of the patient's journey – and thereafter. This happens when the patient – not untypically in the case of older people with a stroke – is the principal carer for a relative who now becomes even more vulnerable at home. One of the patients recruited to this study was such a carer; and one of his main worries upon admission was whether and how his wife would now be looked after. The following is his recollection of how this was dealt with.

In the first interview with this patient in hospital he said he had spoken to his wife and asked 'Will you go in a rest home for a fortnight just so that I haven't got to worry about you and I can make a 100% effort to get out as soon as I can? Because [the social worker] has promised us that once I am out of here you are out of there. Well they went and had a look at it yesterday and it's a lovely private rest home: it's beautiful down there.'

*Q: So when did you see social services?*

*A: He came in the day after I was admitted...he came straight away and he got the ball rolling straightaway.*

*Q: So you don't need to worry about her: that's the main thing?*

*A: That was the main thing.*

*Q: Because she'll be alright?*

*A: Well, as from 2 o'clock today, well as from when [his son] came up last night and said [the social worker] is getting her in to the private home for respite. So I said 'well that's great. I can say, right, that's it'.*

By which he meant he could stop worrying and thereby concentrate 100% on his recovery in order to get back home to look after his wife. Moreover, he had been assured that he and his wife would be offered extensive support by social services when he went home. At a later interview (still on the Stroke Rehabilitation Unit) he said: 'Mind you, the chap from social services, he was

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really good. He said "I can assure you when you come out we will be there for you". Once again, with such an assurance the patient could concentrate on recovery: not worrying about current care or further back-up meant not being distracted, which meant not having care mentally disrupted.

We have tended above to highlight some of the difficulties encountered by the patients recruited to the study. However, in both content and tone the perceptions of their care reported by patients (and their carers) were overwhelmingly complimentary. It is, therefore, appropriate to conclude by quoting the same patient as above. In the last interview with him in his own home in south Tyneside he reported being '100%': in fact he regarded himself as not just being as well as he was before his stroke but better. It's worth noting that although not the densest stroke, he had a stroke severe enough to leave him on admission to hospital with neither feeling nor movement down one side of his body. He was full of praise for the care he had received, especially on the Stroke Rehabilitation Unit: 'The physio that they do, they are really marvellous...it's all down to the physios. I couldn't do anything until they really started on my body...the main thing that got me going was physio. But everyone from the cleaners upwards, you know you couldn't fault anyone really'. When asked about his experience overall in terms of continuity he went on in the following glowing terms:

*They all co-ordinated well. It was a really good unit that. And you had your meetings and you had other people coming in. You've got back-up all the way. It was set out from day one right the way through until I got discharged. And even after you're discharged they don't leave you; you're getting visits and you're getting medical treatment, follow-ups. But in the hospital themselves I couldn't fault them, couldn't fault them in the least, they were fantastic... I don't think you could improve on what they have done.*

## Section 5 Learning disability case study

### **5.1 Introduction and overview**

The second of our tracer conditions used to examine how inter-organisational and inter-professional complexity affects continuity of care within local health and social care systems is the transition from adolescence to young adulthood among individuals with a learning disability. As with our study of older people who have had a stroke, at the heart of our investigation of learning disability transitions is the notion of partnership working across a wide range of agencies, professionals and other stakeholders in the transition process. Partnership working is, of course, far from new – the 1971 White Paper, *Better Services for the Mentally Handicapped*, emphasised the importance of close collaboration between health services, social services and other local agencies. What is new is the nesting of partnership in learning disability policy within a broader Government commitment to joint working, and an expectation on the part of central government that partnership working will be successfully achieved, using a combination of sticks and carrots. The centrality of partnership working stems from the principles, values and objectives of the White Paper *Valuing People* (Department of Health, 2001a), which sets out the Government's proposals for improving the lives of people with learning disabilities and their families and carers based on:

- recognition of their rights as citizens,
- social inclusion in local communities,
- choice in their daily lives,
- real opportunities to be independent.

The White Paper states that:

*Achieving this aim requires all parts of Government to work in partnership. Social care, health, education, employment, housing, leisure and social security all have a part to play, with local councils taking a lead to ensure that partnership becomes a reality at local level.*

(ibid, para 1.3)

Eleven objectives are articulated in the White Paper, the last of which specifically relates to partnership working.

*To promote holistic services for people with learning disabilities through effective partnership working between all relevant local agencies in the commissioning and delivery of services.*

(ibid, para 2.9)

These general imperatives are reflected in the range of other objectives set out in the White Paper, one of which relates to the transition from adolescence to young adulthood. This sets out a specific objective with two sub-objectives to provide a clear direction for all agencies:

*Objective: As young people with learning disabilities move into adulthood, to ensure continuity of care and support for the young person and their family;*



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*and to provide equality of opportunity in order to enable as many disabled young people as possible to participate in education, training and employment.*

*Sub-objectives: Ensuring that each Connexions partnership provides a full service to learning disabled young people by identifying them, deploying sufficient staff with the right competencies, and coordinating the delivery of appropriate supports and opportunities [and] ensuring effective links are in place within and between children's and adult's services in both health and social services.*

(ibid, Annex A)

The most significant implication of these objectives is that since they involve mainstream and specialist services, they will accordingly require the development of complex partnerships, rather than the narrow models which have often characterised separate specialist services. The White Paper notes that:

*The Government's agenda for reforming health and social care, modernising local government, promoting inclusive education and lifelong learning, and Welfare to Work, all offer major opportunities for improving the lives of people with learning disabilities.*

(ibid, para 1.14)

The partnership implications of this model are subsequently spelled out:

*Our objectives reflect the partnership approach which is central to Valuing People and clarify the Government's expectations of all local agencies providing help to people with learning disabilities, and their carers: social services, health, education, employment, housing, the Benefits Agency, transport and leisure services. This is in line with the Government's principles for partnership working enshrined in the Local Strategic Partnerships.*

(para 2.7)

Subsequent guidance on partnership working in relation to the White Paper (Department of Health, 2002c) goes on to identify three implications for partnership working of a socially inclusive model:

- the aspects of people's lives embraced by partnership arrangements must encompass all aspects of a person's aspirations;
- the organisations involved in the partnership must therefore include all those with an interest or responsibility across this full range of issues;
- the partnership must operate with the person with a learning disability and their wishes and interests at the centre.

More recently, the emerging NSF for children (Department of Health, 2003a) looks set to include a theme on transition from children's to adult services for children with disabilities. Whereas much of this simply re-iterates *Valuing People*, it differs in two important respects. First, the backing of standards derived from a NSF will give greater urgency to the transition issue. And secondly, there are some new measures being proposed. In particular, it is stated that a 'Transition Group' will be formed in every relevant locality to develop multi-agency transition strategy and services. Membership will comprise the Transition Champion from the Learning Disability Partnership Board (a position that often seemed to be unfilled) and representatives from the Connexions Service, LEA, LSC, the 'Health Economy' and social services – a far more formidable body than the front-line transition sub-groups that typified our localities. Moreover, these bodies will be set 'challenging,

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measurable targets that will lead to tangible service improvements over a ten year period'.

### **5.1.1 Analytical framework**

The framework we will use to set out our findings around continuity in learning disability transitions is an adapted version of that arising from the multi-method review undertaken by While *et al.* (2004), which itself builds upon that developed by Haggerty *et al.* (2003). We found the most relevant dimensions to be as follows:

- inter-agency continuity: relationships between multiple services both horizontally (within each age-band structure) and vertically (between services concerned with children and those concerned with adults);
- inter-professional continuity: relationships between multiple professionals both horizontally and vertically;
- personal-professional continuity: the availability of one or more named individual professionals with whom the service user can establish and maintain a relationship.

These three are supported by two further issues, namely the identity of the co-ordinating body and the flexibility of individuals and organisations.

## **5.2 Inter-agency continuity**

### **5.2.1 Horizontal inter-agency continuity**

There are two main service worlds relating to children – those of education and social care. In addition the role of Connexions is now beginning to come into focus. Although all children with a learning disability will have had access to education, not all will be deemed to be in need of social care support throughout childhood. Nevertheless, as school-leaving draws nearer, it is expected that links between the education service, social services and a range of other organisations and professionals will grow closer for all young people with a learning disability.

The formal situation in relation to transition planning is explicit about the steps to be taken, the parties to be involved, and the scope of the exercise. The primary policy tool stems from the Education Act 1993, and the associated *Code of Practice on the Identification and Assessment of Special Needs* (Department for Education and Employment, 1994). This requires that any young person who has a statement of special educational needs should also have a transition plan drawn up by the LEA at the first annual review of their statement after the 14th birthday. This should be reviewed on an annual basis and should cover what will happen after the young person reaches 16.

The transition plan itself is supposed to draw together information from a range of individuals within and beyond the school in order to plan coherently for the transition to adult life – a holistic approach that touches on all significant aspects of the young person's future life. The Code states that the head teacher, who has delegated responsibility for managing the review, must invite contributions from a range of people, including the parents of the child. The guidance stresses the importance of partnership with agencies and

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parents and is explicit about the importance of taking account of the young person's hopes and aspirations.

A revised Special Educational Needs Code of Practice came into effect on 1 January 2002 (Department of Education and Skills, 2001) to reflect developments that have taken place since the earlier Code was published, such as the Learning and Skills Act 2000 and the establishment of the Connexions Service. It sets out the head teacher's formal duty to write a transition plan for a child in Year 9 with a statement of special educational needs, where the child is in school. Mandatory invitations extend to an LEA representative, Connexions, and a representative of social services, so that any parallel assessments under legislation can contribute to, and draw information from, the review process. Section 140 of the Learning and Skills Act requires an assessment of the young person in the final year of compulsory schooling, where this young person is likely to move on to post-16 education or training.

This is all seen as the culmination of an ongoing assessment and review process that has been going on since the Year 9 transition plan. Throughout, a wide interpretation of the meaning of transition is applied. It is made clear that transition planning is a continuing process that should be concerned not simply with leaving school, but with the move to adult life generally, covering all aspects of the young person's development, and specifically including topics like self-advocacy, personal autonomy and the development of independent living skills.

Policy implementation is rarely straightforward, and the Special Educational Needs Code of Practice in relation to transition planning appears to be no exception. Much of this is at the level of inter-professional relationships, but this can be difficult to disentangle from inter-agency relationships. A particular issue emerged around discontinuity of information, where communications between some of the key partners in transition planning sometimes caused problems. Several types of communication difficulty can be identified.

### **Communication mismatching**

In one case the issue was as basic as confusion over where to send invitations to review meetings:

*Letters have been going to the wrong buildings, so that social workers haven't been getting their invitations until after the meetings happened...everything is sent to Central House, but the teams aren't there any more.*

More fundamentally, there was sometimes confusion about the role of the LEA in using transition data and taking a role in forward planning. One senior manager in an LEA saw her role as alerting schools to the existence of those children who should be having a transition planning review. While acknowledging that schools should (and probably would) already know of these children, she still saw the LEA role as an inescapable responsibility – one of 'ensuring schools understand their responsibilities for procedures' – existing knowledge of which was felt to 'vary from school to school'.

Additionally, the role of the LEA was to gather in the completed transition review plans across the locality 'to enable the LEA to review the statement', even though 'we wouldn't take the plan and scrutinise it and comment on the

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quality'. There was no evidence either that the LEA used the totality of reviews to inform forward planning processes on anticipated service provision to reflect needs identified in the plans. For one head teacher this sort of relationship seemed too much to bear:

*I have no idea what they do, no idea. I produce all these annual reviews for all of my children, and I don't know if anybody ever reads them. At one time the LEA said to me they only wanted one side of A4 of the child's educational progress, and I said I am not playing that game, this report is for the parents. I don't know what they do, I really don't know.*

Others felt that 'education' was the weak link in the co-ordination chain:

*I haven't got a problem with the health and social services side of things; it's education that isn't joined up. I'm not even convinced the LEAs and the schools are joined up.*

(Integrated Commissioning Manager)

From the point of view of the LEA, the problem was the increasing autonomy of the schools and the increased amount of funding going directly to schools that would previously have been channelled through the LEA:

*The biggest problem I have is that the Government has chosen to give so much money to schools. Very little is left behind here.*

(Head of Access and Inclusion, LEA)

### **Communication delays**

It was not uncommon for families to be left in limbo until quite late in the day as to the nature of post-school destinations. Sometimes this arose from ongoing disputes over the funding of placements between social services and the LSC, but sometimes simply from a failure to relay decisions to families in a timely manner.

*I didn't get the letter about funding his placement until the 6-week holiday period... I still wasn't sure from him leaving school until into the holiday whether there was a guarantee of funding.*

(Parent)

It is not just delays in communicating information to parents – there is also evidence of poor communication between agencies concerned with children. In one locality it had proved very difficult to extract even the most basic information from the LEA to other partners:

*It took us 3 years to convince the LEA that if they gave us information we would not abuse it – that we wouldn't send out lists of names willy-nilly, and we would safeguard confidentiality.*

(Transitions Coordinator)

### **Communication closure**

Here, there is information available that could usefully feed into transition planning, but the channel of communication is ostensibly closed. One children's services manager in the voluntary sector felt that the data held by her organisation represented a missed opportunity:

*We're not considering the knowledge that people have here around young people. We're working with them all of the time, 50-odd weeks a year, and we*

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*have a low turnover of staff, but nobody's asking us for the information. That's frustrating me.*

For one parent, the failure to disclose evidence and information at planning meetings was a long-standing source of resentment:

*I never knew what the psychologist did or where he got his report, I never knew when he had his meetings with Barry. I used to get narked by him. He just used to come in with his briefcase, nod a couple of times, have a coffee and go.*

(Parent)

Indeed, in one locality, it appeared that the rapid closure of transition-planning reviews has become institutionalised:

*We've had amazing conversations with the schools for children with severe learning disabilities, reporting that they held Year 9 transition meetings that were over in 20 minutes. The reason they were over in 20 minutes was that nobody came.*

(Strategic Manager, Children's Services)

Less-frequently mentioned partners were also liable to hold on to information rather than communicate it:

*The acute health trust has extensive health records of children accessing their services, but it goes nowhere. It gets archived at 16 and that's it.*

(Valuing People Officer)

### **Communication gaps**

In this situation, information does exist, but fails to be communicated in appropriate ways, if at all. In one locality, for example, the Transitions Coordinator used a list of young people supplied by the LEA to assess future needs, but this list did not include those in out-of-area schools, or those who had another disability – typically physical disability – as their 'primary statement'. From the family perspective, one key communication need was for a comprehensive account of post-school options, but none of our sites had yet been able to produce a comprehensive package of information.

*There should be a road map that says 'Right, at the age of 16 we start the planning procedures. What are the requirements of the child? What is going to happen and when?' It's not rocket science. It's done every day of the week, it's called project planning.*

(Parent)

In the absence of any such guidance, some parents looked elsewhere for information and support:

*He really needs a voice box so he can communicate. Who do I go and see? My GP? Social services? I don't know who to ask. They've started fundraising at the local pub to see if we can raise the funds to buy one ourselves.*

(Parent)

*We don't know what jobs and what options are open to him. We could ask at supermarkets if they have got vacancies.*

(Parent)

But not everyone felt capable of trawling through information packs:

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*I don't know about packs. I'm not too good on written information. I prefer talking to people.*

(Parent)

The production of an information pack seems an obvious and relatively simple measure to introduce, but as Smart (2004) has argued, discontinuity between the aims and objectives of parents and those of the agency concerned can make this a contentious matter.

### **Communication confusion**

The number of multiple and overlapping assessments that might feed into the transition reviews was increasingly recognised as unsustainable and confusing for young people and their families:

*There's a nightmare on assessments. Everybody does their own, and the parents and young people get fed up. Schools do assessments, we do assessments, Connexions do their assessment, the Transitions Coordinator does an assessment, the adult services come in and do their assessments, and then health come in and do one.*

(Children's Services Manager)

And even in those situations where, at least from the perspective of the parents, the transition review had gone well, implementation could not be assumed:

*Everybody who knew her was at the 14+ review and we all agreed what should happen. It was all going well, but then it didn't happen. I just feel they promise you all these things and then it doesn't happen.*

(Parent)

## **5.2.2 Vertical inter-agency continuity**

### **Social care: children's and adult services**

For most children the service world prior to the onset of young adulthood is dominated by the education system. However, whereas for most young people the dependence upon services *diminishes*, for those with a learning disability there tends to be a *transfer* from one set of services (for children) to another (for adults). For Heslop *et al.* (2001):

*This is not simply a case of moving from one otherwise similar set of organisations targeted at children, to a parallel entity concerned with adults. Organisational 'discontinuity' is certainly a factor, but reality is more complex than that. The two sets of services tend to be organised in different ways and to have very different cultures... The resulting lack of coordination has been widely recognised if not always fully understood.*

(p.7)

As with transition planning *per se*, this transfer is not without legislation, guidance and exhortation. A range of legislation sets out the duties of social services professionals to provide support during the transition period, as follows.

- The Disabled Person's Act 1986 requires links between education and welfare services at the end of education. It gives LEAs and Further Education Funding Councils (now the National Learning and Skills

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Council) specific responsibilities for ensuring that students with statements of special educational need are known to social services departments, and that plans are made for them.

- The NHS and Community Care Act 1990 provides the legal framework for community care services, giving local authorities responsibility for the co-ordination, planning, assessment and arrangement of services for adults with health and social care needs. Young people in transition to adulthood are entitled to an assessment of their needs under this legislation.
- The Quality Protects Initiative was launched in 1999 with the intention to transform services for vulnerable children and their families. Within this, effective support for disabled children and their families is a priority, including further consideration of the transition arrangements for disabled young people moving from children's to adult services.
- The *Valuing People* White Paper states that directors of social services are required to ensure that good links are in place between children's and adult services for people with learning difficulties as part of their responsibility for quality under the Social Care Quality Framework. Local agencies were also expected to have introduced person-centred planning for all young people moving from children's to adult services by 2003, and Learning Disability Partnership Boards have a responsibility to ensure that good transition services are in place.

The wider evidence on the extent to which this is fulfilled is not promising. Heslop *et al.* (2001) reported that 43% of parents of young people who had received some transition planning reported that the transfer to adult social services had not been dealt with at all, whereas only a quarter thought it had been covered well. Where the process was handled well, it had been co-ordinated by a dedicated key worker – a point discussed further below – but others felt caught between two stools. Indeed, the Social Services Inspectorate inspection (Social Services Inspectorate, 2003) reported that transition into adult life threw up the highest number of complaints from carers, and that difficulties arose from poor communication between children's and adult social services. In our own work, one parent objected to the very idea that transition was 'handled':

*The transition isn't handled, it's like an accident. You come to it and it happens. It isn't handled, nobody's prepared for it. The school does its end as far as it can and the other end doesn't get handled at all. It's like building half a bridge and expecting somebody to jump the rest of the way.*

Our work reveals four discontinuities in the relationship between children's and adult social services: informational, financial, organisational and chronological.

### **Informational**

In principle it should be straightforward for local agencies to identify young people with disabilities and use information for planning purposes in a rational and timely way. However, the Social Services Inspectorate (2003) report notes that:

*This happened only rarely in practice, due to the disjointed nature of the information systems of the various agencies involved. Health and social*

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*services systems were almost always incompatible, making it more difficult to share information. Even where systems were compatible, the maintenance and use of the database across different departments was still a problem.*

(para 3.9)

Whereas this may be a disappointing – if predictable – finding on information flows between different agencies, it is reasonable to assume that information flows between children's and adult services within the *same* agency will be better. This does not always seem to have been the case in some of our sites. In one site it was proving to be unexpectedly difficult to even identify a list of children who had a social worker, a situation put down to the disinclination of social workers to update their records – 'I think social workers are very busy and things like updating the computing system are not at the top of their list'. The most common difficulty, however, concerned the general availability and quality of information. In one case, the adult service was attempting to introduce a common informational format so that children's services' colleagues could more easily identify and provide the information felt necessary for forward planning:

*In adult services we feel the way people's case files are handed over, the relevant documentation we need is not actually present. I have drafted a format for discussion but I know this is going to meet with resistance, because everybody is going to basically say they don't have time to fill anything in.*

In a different site, it was lamented that the only source of information was the statement of special educational need, and that even this was of limited value in transition planning. One officer was able to refer to a continuum of information. At one end are children who are known to social services teams and on whom there are files available to the adult teams. In the case of 'looked-after' children, this information can be quite extensive where they have had their 6-monthly service review. Children who have a statement but no previous connection with social services come next on the continuum, with some concern that the information on the statement is of limited value in planning for adult life. Some young people without a statement may have gone to college, and there may be access to their application form or to information held by Connexions. And finally there are some cases – usually from other localities – where young people are referred from a variety of sources and have no accompanying documentation whatsoever.

### **Financial**

The impact of financial discontinuity was summed up in the Social Services Inspectorate (2003) report:

*Adult services were sometimes reluctant to accept service users who had been receiving expensive care packages under the children's services umbrella... Budget pressures and competing demands on limited resources exacerbated this problem.*

(para 3.11)

The contrast between the relative plenty of educational services and the relative penury of other parts of the system was often acknowledged by parents and professionals alike. In one special school for severely disabled children, 120 computers were available and almost every child was said to be computer literate. Those that weren't had the use of switches and



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technological aides such as voice boxes. The school acknowledged that some parents were shocked to discover that not only was such generosity rarely available in adult services, but that some adult services also attracted a payment. The most prominent example is respite care, which is free to children but incurs a cost for adults. Although parents understood that this arose from the receipt of social security benefits, they nevertheless found the situation difficult to accept, especially when it was combined with more limited access.

*In children's respite I was allocated five nights a month for him and now I've only got 20 for the year, and they charge £10 a night.*

One family in our sample was fostering two young people with learning disabilities, triggering eligibility for both a looked-after child allowance and an additional allowance because of the children's disabilities. In one review meeting they felt the need to raise money as a critical factor in the transition planning for the children:

*We had to say at one meeting in school that we didn't even know where he would be living when he is 18, never mind what he's going to do in his life. It was the first time we had been so honest. It was a bit emotional really and frightening to think that it all hinged on finances when we have got that loving bond as well. It sounds silly doesn't it, but finances are a massive issue.*

The ways in which financial support are channelled through different agency routes, regardless of the needs of the recipients, caused additional problems at the point of transition. Although, as we note below, there tends to be a 'comfortable continuity' between school and college, this relationship has its own perverse incentives in terms of ensuring a continuing presence in the learning environment:

*There is a huge conspiracy to keep young people in school until 19 and it's all about Further Education Funding Council [FEFC] funding for college placements. If they stay in school until they are 19 they can still get their 3 years FEFC funding that will take them to 22, but if they leave at 16 and have 3 years FEFC funding then at 19 people are saying 'what are we going to do with them?' It doesn't feel right that 100% of them will stay at school.*

(Children's Services Strategic Manager)

More obviously, an earlier move to college involves a loss of income for the school, and this can lead to an unseemly tug-of-war in which the best interests of the young person become a matter of dispute:

*We thought it would be a good idea for him to leave at 16 because his education had come to a standstill, and the social worker agreed and phoned up some colleges. The school wasn't helpful and said he wasn't mature enough to leave at 16. We had to appeal because he was going at 16 rather than 19.*

(Parent)

A smaller but similar consideration applied in the same authority to transportation to colleges outside of the authority's boundaries – a critical limiting factor for many young people with a learning disability:

*Young people get supported transport to the local [further education] college, but if they opted to go to a college slightly further afield they wouldn't get that support. It feels like there is this huge convenience factor that reinforces the status quo, rather than focusing upon the needs and wishes of young people.*

(op cit)

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A similar problem of budgetary transfer operated at an inter-agency level, especially in the case of a small number of very expensive young people with very complex needs. In one case, a placement for a 17-year-old was costing around £200 000 a year, and the cost was a matter of some dispute between social services, education, health and the LSC.

For some managers, financial bargaining with other agencies about funding responsibility had become a way of life:

*I argue quite frequently when people come to us. I look at what their health needs are and begin a dialogue with health. I might request 50-50 funding or 70-30. Yesterday I sent in a request for 100% funding.*

(Social Services Manager)

### **Organisational**

Again, the Social Services Inspectorate (2003) sums up the problem:

*Families have a right to a reasonably seamless handover from children's to adult services; they should not be left in the dark wondering whether or not services will continue into adulthood. Above all, services should not be compromised by demarcation disputes between different council and health departments.*

(para 3.3)

The financial discontinuity referred to above is one consequence of the deeper issue of inter-organisational fragmentation. Many dimensions of inter-organisational fragmentation between children's and adult social care services could be identified. Unlike some intersections, there was more reliance upon informal relationships rather than formal structures to sustain relationships – a strategy that may work well where the inter-personal relationships are strong, but one doomed to failure where these are weak, or where the task of co-ordination is entrusted to someone who lacks the authority to bring about a re-ordering of relationships. As one front-line worker with just such a remit noted, 'I would like to see the teams brought together a lot more to discuss things, rather than me being the person who is running back and forward all the time.'

The handover from children's to adult care could also be hampered by operational fragmentation within children's services. Where young people with a learning disability do have contact with children's social care, this may come from one of several distinct teams – in one site this covered the disability team, children in need team, children and families team, child protection and looked-after children. A community nurse commented on this situation: 'you have got a number of interfaces with social services, but no integration'. The impact of this organisational fragmentation may be greater where there is no specialist support in the field of learning disability.

In one of our localities this position was potentially further complicated by the fact that the children's service provision, including the social work role, had been outsourced to a voluntary organisation, with adult social work services still held in-house. The level of continuity between the children's and adult services was accordingly complicated, with the adult team stretched to undertake the agreements that had been made.

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*We have a care leaver, he's 18, been on a full care order. We asked social services to get involved with him just after he was 18 and he still doesn't have a social worker assigned to him from adult services. We keep pushing social services to take them on, or we'll be back in situation of 4 years ago where we still had people at 22. Because of that we had an agreement that they would take the complex cases at 16 and everybody else at 17, but they are just so short-staffed.*

(Children's Services Manager)

Parents often found the re-arrangements puzzling and frustrating:

*It's hard because you get a new social worker and they don't really know you. Barnardos knew her from being a baby and then suddenly, at this big time in her life, you lose your social worker as well. It's a pity you can't go on until you see them settled into adult life.*

(Parent)

This operational gap between children's and adult services can be reinforced where there is also strategic fragmentation. In one site, for example, strategic issues for people under 18 were dealt with by the children's strategic partnership, whereas those for adults fell within the remit of the Learning Disability Partnership Board, and it was proving to be difficult to get overlapping membership of the two bodies. It seemed that strategic inter-agency decisions on the division of operational responsibility had typically not been taken, leaving operational staff to sort things out – or not – at the front-line level. This was especially true of the contribution of the new breed of Connexions Personal Advisers (PAs).

However, the most frequently cited explanation for the gulf between children's and adult services revolved around differences of approach or 'culture' – a difference that went as deep as the very meaning of the concept of transition:

*There is a misconception by children's services about what transition means. For them the focus is narrow, on children they are currently looking after, either in respite or long-term care. They don't see it as the wider population of people with a disability.*

(Manager, Social Services)

For one front-line worker, the perceived insularity of children's services had resulted in a lower commitment to inter-agency working than was the case with adult services:

*The impression I get is that adult services are doing quite a lot of inter-agency work, whereas the children's services carry out solely a social work role, its not about corporate working.*

In a different site, an adult social care manager emphasised the difference in time span between the two services:

*Children's services tend to be reactionary, they will plan to get a child through a crisis, not to plan for people after 18. It's a targeted model, a quick in-and-out approach, they don't take a long-term view.*

This view was echoed by a Connexions Area Manager elsewhere:

*One of the problems as a whole has been the very sharp divide between children's and adult services. Our experience has been that the children's services are interested in the here and now until they are 18, and then it is the adult services who take over.*

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All of this can be reinforced where there is informational discontinuity between agencies and professionals. In the authority that outsourced children's services to the voluntary sector, for example, joint assessments with adult services were hampered by the fact that voluntary-sector staff could not access the information systems of the local authority. In the same authority it was noted that:

*We haven't sorted out our computer systems. The adult services aren't able to carry out an assessment on anybody under 18 because the computer won't allow it. You enter the date of birth and they are not eligible for processing on the system.*

(Children's Services Manager)

### **Chronological**

The relationship between service provision and chronological age is important but unclear. It has several dimensions. First, it is related to a significant loss of service per se – something for which parents are not always prepared. Physiotherapy, occupational therapy, speech therapy and psychiatric help, for example, may all be severely curtailed once a child is deemed to have reached adult age. And as one respondent observed: 'It could all happen in one go, or it could happen gradually'.

As has already been noted, disputation about age-related service responsibility may be related to disputes about budgetary responsibility.

According to one front-line worker in adult care:

*I'm aware of 14- and 15-year-olds who are complicated, but I only become actively involved when they are 18. I would do some work from when they are 16, at 17 I would co-work a case, and at 18 I take it on. The problem I have is that the children's team have been passing the 17 year olds to me in their entirety, but we can't take funding responsibility until they are 18.*

A similar situation applied in a different authority in respect of nurses for young people with disabilities:

*The two nurses for young people with disabilities are based in the Child and Adolescent Mental Health Team that only works with young people up to the age of 16. You have got this gap between 16 and 18 and people have literally been falling through it. There needs to be some sort of give and take – some flexibility.*

(Adult Social Services Team Leader)

The situation is complicated where agencies have different ages for withdrawing different services – in one locality, for example, in addition to the difficulty around handover between children's and adult services, children's physiotherapy stopped at 14 and speech therapy at 16, unless the young person was still at school, in which case it continued until school-leaving. In this same site, specialist community nurse support did not even operate with a cut-off point – 'we take it on an individual basis'. This is a confusing situation for young people and their parents, but at times it also seemed to bemuse the professionals involved:

*I've never had any clear feedback at what age a young person would not be seen to come into children's services...that's something that's not clear to me to this day.*

(Community nurse)

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Whereas some services had sharp chronological cut-off ages, albeit different ones, paediatric care seemed to be more a matter of professional discretion:

*The doctor came into the school once a year, but now Chris is seeing her at the hospital. The last time she saw him at school she said she didn't want him to change to anybody else, so I thought that was really good of her.*

(Parent)

*Barry was seeing a paediatrician when he was way over the age limit. He was treating his skin problem and just said 'This will have to be the last time I see you'.*

(Parent)

The extended duration of transition was seen as exacerbating the situation:

*You can't be fine art about dates and times in transition. You have got to look at a span in terms of time that probably starts at 16 and goes up to 25, and make sure there is a proper kind of communication flow. What's tended to happen is people have worked in silos against specific dates. We have got to have dialogue much much earlier in the process.*

(Senior Social Services Manager)

The abrupt service deficit arising from chronologically based eligibility criteria was a constant cause of distress to families:

*Once they reach 19 and leave school they might as well not exist. It's as bad as that and it goes back donkey's years.*

*I don't think the authorities see that though they might be adult by a birth certificate, the same problems are there. To me the service should just carry on, it should follow straight on through adult life. It shouldn't change, you shouldn't have to fight for what you had.*

For service managers, the challenge arising from this was to manage parental expectations to more manageable proportions:

*There are issues around parental expectations of their children receiving a certain set of resources. Obviously there may be a change in terms of the services they receive and that is actually appropriate, but obviously parents don't see it that way.*

(Senior Local-Authority Manager)

### **Social discontinuities**

A further discontinuity directly related to the transfer from children's services to adult services relates to the loss of so-called social capital. In the past, the tendency was to transfer cohorts of young people from special school to adult training centres. Although now widely seen as unacceptable forms of support, adult training centres did retain the social capital that had been built up between young people and parents throughout the school years. A number of respondents regretted the loss of this resource:

*Once your teenager reaches a certain age you lose contact with the parents. At primary school you meet in the playground or wherever, but with special school and college you put them in a taxi or bus every morning and wave them goodbye.*

(Parent)

*It would be nice if there was a network of families happy to have their phone numbers put down. Social workers don't know what it's like as a parent when*

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*you are feeling low. By the time you come off the phone with someone else going through the same thing as you, everybody feels much happier. All you have done is have the moan and whinge you were looking for in the first place.*

(Parent)

*I don't know many other mums or other people in the same situation. In school we did see each other occasionally, but now he's at college I don't know any of his friends or their parents. You used to pick up information from the other kids but that doesn't happen any more.*

(Parent)

*There is seven of them in transition at the moment. They keep asking them what they want to do, and all they say is 'we want to stay together'. But they won't – there just isn't the money.*

(Parent)

In one of our localities, the demand from young people themselves to stay in contact with each other had led to a shift in thinking about the way in which post-learning opportunities were to be provided:

*The young people were saying that they liked being in groups and being in contact with each other, rather than being given individual things. Currently there is not a way to keep them together. We are starting to think about getting them to work together as a team but producing something valuable at the end of it.*

(Transition Worker)

### 5.2.3 'Comfortable continuity': from school to college

Other studies have noted that the transition process can be attenuated where there are few post-school options available. Heslop *et al.* (2001), for example, argue that 'good practice would suggest that young people should be given the chance to try out options and/or make visits before leaving school' (p.30). They found this to be the case in only half of the young people in their sample who were still at school. Our sites varied in the extent to which this happened. In one area there was a scheme that offered just such an opportunity, and this was highly regarded by young people and their parents. In another locality there was little choice or opportunity, and some people felt this undermined the *raison d'être* of the transition process.

*It must be difficult for them to have to say there is nothing available for your child, I am sure there is anger expressed towards them, it's uncomfortable. The conditions, in my opinion, mimic the 60s, but certainly not the 21st century.*

(Parent)

In one authority, parents saw the effective choice at school leaving as being either college or a residential placement:

*You either go to college or you leave the borough altogether and go residential. You can do both, but you have to go to residential first and then come back. You can't go to college and then go out of the borough.*

One parent drew a contrast between the ostensible content of the statement of special educational need, and the reality of provision:

*You can produce special educational needs statements and the parents say 'oh goody, this is what we are getting'. No, it doesn't mean that, it means this is*

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*what you need, not what you're getting. The transitions document is what we need but not what we are getting.*

One college course manager agreed that in reality most people assumed that young people would simply leave school and attend college, and this has the potential to undermine any consideration of options and preferences. A head teacher in the area was aware of this issue and was accordingly reluctant to invite the college to the transition review:

*That would be almost pressuring parents about making a decision for the college, and I want the parents to be able to have the opportunity to choose which is best for the young people without any pressure.*

Where genuine choice is so limited, local agencies could find it difficult to encourage young people and their parents to think more broadly about their preferences. One local children's services manager identified discontinuity of expectation between children's and adult services in this respect:

*We drew together a lot of information about needs and strengths, and about who was going to do what, where and when. Adult services weren't happy about those because they felt it built expectation. I wanted to know what was wrong with expectation. These were assessments concerning the essential things in people's lives, but adult services weren't happy about it, so we stopped doing them.*

Rowland-Crosby *et al.* (2002) also noted the problem that colleges are seen as the *only* progression route for most young people, even though the choice of courses and opportunities is restricted. Heslop *et al.* (2001) similarly found that almost 80% of the young people in their study, who were in their first placement after school, were in further education. There is something of a transition paradox here, in that whereas most students left school for further education, there was little or no involvement of further-education staff in the transition planning. Sometimes this was despite the best efforts of the school to encourage attendance, but in another case the head teacher took the view that it would be wrong to invite a 'preferred provider' to the transitions meeting, since this might skew a discussion of alternatives.

Some people in our study were concerned about the quality and relevance of the courses young people were undertaking:

*The college has been quite good at getting people on to courses they currently run, traditional pathway-type courses, but has not been innovative about attracting students who don't fit that model. The college needs to stand back and take a broader view. If they provided more vocational training for some young people, they could make a really good contribution.*

(Social Services Manager)

Another manager with employment responsibilities disliked the very notion of sending young people to a 'special' and segregated college course:

*I use the community education service with ordinary members of the public, not special courses in college. In my opinion, college is just another adult training centre. I want my people out there, shoulder to shoulder with everyone else.*

A head teacher similarly took a jaundiced view of what was on offer:

*My students went to a college open day and came back saying 'I don't want to go there, thank you, it's a load of rubbish'. That was a group of our young people making a judgement about what they had seen and experienced. And from what the staff said, it was a very fair judgement they were passing.*

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For one local-authority officer, the available college provision seemed to replicate many of the problems of traditional day centres:

*We have almost exported our day centres to colleges, setting up little enclaves within colleges to do rather mundane, routine things.*

Colleges in turn were seen as being in thrall to the performance-management demands of their funding body, the LSCs:

*The outputs [that] LSCs demand from colleges are based on throughput and bums on seats – you have got to get 23 people through this course in 6 months, they have all got to be NVQ level 2 or whatever. Some of it just doesn't fit with learning disabilities.*

One service user also felt that the support she received was inappropriate. In her case, the school staff offered some transitional support into the college setting, which worked well, but once this was removed the situation deteriorated:

*When the teachers left, the tutors started treating me like a child. I wasn't allowed to go anywhere on my own. I was in hospital nearly every day because I kept having a seizure and they were panicking all the time. I chose to leave because it was doing my head in.*

Part of the critique of continuing education was the poor links to subsequent employment opportunities and experiences. Heslop *et al.* (2001) report the popularity among young people of work experience or link placements that provide 'fresh experiences, a sense of the next step, a time to accommodate to new locations, and a way to inform choices' (p.89). One of our localities offered just such a service as part of the transition experience. In this case, there is an introductory period before school leaving where the students sample a range of services over a 2–3-month period. One social services manager thought that while this was popular with the students, parents were less enthusiastic:

*Parents hate it, to be honest. A lot of them are really resistant to allowing their children to go into the service. What they want is a traditional day service, very predictable times of the day, very similar to school.*

The crucial issue here is the range and quality of services on offer, and the extent to which they form a coherent route at the end of the transitional support. The underpinning issue here tends also to be cultural – the conception of transition that is held by the various stakeholders. Notwithstanding the strictures of the Code of Practice, O'Bryan *et al.* (2000), claim that most planning does not extend beyond the immediate move out of the school, with further education seen as the preferred 'default' option by both professionals and families. In particular they argue that transition planning might reasonably be expected to include an attempt to explore the possibility of employment, but conclude that 'few participants in the transition process appeared to have any expectation that young disabled people could work'.

This was confirmed by the work of Heslop *et al.* (2001), who point to the broader mismatch between the expressed needs of young people and the more limited conceptualisation of transition held by many professionals and some parents. They report that the topics most frequently covered in transition planning were opportunities for further college education, independent living skills, adult sexuality/relationships, careers and



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employment, and speaking up for oneself. The topics that many parents *wanted* to be covered – but which were normally not – were leisure/social opportunities, information about benefits, future housing options, transfer to adult social services, and transport to post-school provision.

There is an issue here about the ways in which different transition stakeholders conceptualise the notion of transition. Commenting on the short-term nature of much transition work – that is, the focus upon post-school education provision – Heslop *et al.* (2001) found that many parents felt that the point of school-leaving was indeed too early to begin imagining future possibilities. To the extent to which young people with a learning disability are seen as 'children', then the tendency may well be to mentally close down many of the options that would be considered for other young people. One head teacher in our study, when asked whether the review meetings ever considered issues other than education, simply replied 'residential'. For those with a wider conceptualisation, this could be a frustrating time:

*Some of the reviews you go into, you just think 'what was the point of that?' I could have just had a conversation with the teacher, found out how they were doing in maths, English, science, and whether the young person likes school or not. I probably know about this before I go into the review.*

(Connexions PA)

*Schools tend to take the attitude 'well this is just an educational review' and we tend to take the attitude 'no, it's a planning for later life review'. It's been difficult to get over that.*

(Valuing People Officer)

In one of our sites there was a recognition of the crucial role played by organisational culture in shaping the anticipated outcome of transition planning – and in particular this view that the prevailing culture in education was too narrow. One social services policy officer commented:

*We have been trying to get round the schools to talk to them and help them see the situation not just from the point of view of the Education Act, legal requirements, Ofsted standards and so forth, but to see it as 'what's going to happen when they leave and go out of the door'. That's the perspective that has been missing in schools. Their job has been almost to get them to 18, but it hasn't been clear what sort of future they are preparing children for.*

This situation was seen as a reflection of the organisational discontinuity between education and adult social care. It was suggested that:

*There is almost a greater gap between adult social services and education in the same authority than between social services and health. That needs to be in place, otherwise schools may not be clear what they are preparing children for.*

This can be a crucial issue where the cultural dissonance is high, as was suggested by the same interviewee:

*Parents go to schools and say 'what's available?' and if the schools have limited knowledge and are not up to speed with Valuing People, then they are going to stitch the whole thing up. They will shape parental expectations with 'well he is never going to get a job of course'.*

Although most of the parents in our sample were pleased about college entry, they were only too well aware that this constituted little more than a postponement of the 'real' transition into adult life:

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*His transition from school to college has been very smooth. It's the rest of his life that's the worry.*

(Parent)

*We always wanted him to go to residential college so we didn't have the problem of 'what are we going to do next'. But when he comes home next year, that will be a major, major problem.*

(Parent)

Overall then, there tends to be some dissonance between the rational, holistic model underpinning the Code of Practice, and the reality of implementation, and much of the difficulty arises from matters of inter-professional and inter-organisational relationships. In particular, there is a tendency for the focus of legislation and guidance to be upon the transition from leaving school, whereas for many young adults the crucial transition is that which occurs after college, typically 3 years later.

### **5.3 Inter-professional continuity**

#### **5.3.1 Horizontal inter-professional continuity**

Much of the difficulty here related to the looseness of professional relationships during the transition planning process, and in particular the limited range of involvement at what are ostensibly crucial milestones in the young person's progression. It is clear from the Code of Practice that a wide range of professionals is expected to be involved in transition reviews – in principle the range of attendees might be expected to match the complexity of the issues to be addressed. Given the multi-faceted nature of transition, this principle might be expected to trigger widespread attendance. In reality, a recurring difficulty across our sites was the paucity of attendance at transition planning reviews, with comparisons often drawn between who ideally should attend, and who actually turns up.

*There is a member of the management team who runs the reviews and chairs it, and the class teacher, hopefully somebody from the children's disability team, sometimes people from respite...you might have 10 people. But at some you only have the teacher and the chair.*

(Deputy Head Teacher)

*There have been concerns raised that the 14+ review has not been well attended at all...that social workers haven't gone, and there hasn't been much information released from it.*

(Transitions Worker)

*Nine times out of ten you literally have me, the teacher and the pupil at the review.*

(Connexions PA)

Parents felt particularly aggrieved about poor professional attendance, and often interpreted it as an indication of the low priority being accorded to themselves and their children.

*At the transition review, only the head teacher, class teacher and careers officer turned up, and the careers officer didn't speak. In my opinion it's the most important review of a child's school life. I thought, this is my child's life...I was so angry.*

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*Oh you had your reviews at school with the head and the teacher. They had reports from speech therapy, careers never used to come. That's all there was – the teacher, me, him and the head.*

*Nobody turned up for his 14+ review, only me, his dad and the teachers from the school. I was very angry at all that, it was his future. I felt let down by the authorities, it was like it didn't matter.*

*The last meeting there was myself and the teacher. There's hardly anybody there at a meeting, but they are all invited.*

(Parents)

Several explanations were put forward for this situation.

### **Workload pressures**

Where transition work is simply tacked on to existing duties, there may be both an unwillingness and inability to undertake the necessary tasks. Cohen *et al.* (1998), for example, refer to lack of time and administrative support for school nurses, shortage of time for social workers and therapists, and insufficient time for all staff to attend transition reviews. This was re-iterated in our fieldwork, along with the allied issue of staff shortages, especially in the fields of medicine, educational psychology, speech and language therapists, occupational therapists and physiotherapists. Indeed, some parents had never seen certain professionals:

*I hear people going on about 'oh the educational psychologist came' and I'm thinking 'we haven't heard from one of them'. I don't know if I'm supposed to get in touch with them or whether they are supposed to get in touch with us. We just don't have any dealings with them, it's very peculiar.*

(Parent)

### **Individual professional discretion**

To quite a large degree, individual professionals seemed to have discretion as to whether or not they prioritised attendance at the transition review. For some, it may have been a simple matter of competing priorities:

*If I was involved with the child I would make the best effort to go along, but if child-protection issues come up, you have to drop everything. It's very much about what's going on at the time.*

(Community nurse)

The example of child protection as a higher priority was used on more than one occasion, but it was not evident that child-protection duties routinely clashed with transition review duties. A manager of a children's disability team expressed his exasperation at the failure of his team to prioritise attendance at reviews:

*I am furious that he didn't attend, because it is so important, I have asked that all my social workers attend them. I debate the priority that was in his diary, we all have clashes of appointments, but I think he made the wrong choice.*

However, some saw variation in attendance to be a legitimate reflection of the complexity of a specific case, with the inference that not all professions and agencies necessarily had to be present at a transition review:

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*If a young person has already got a social worker and is using respite care, they are much more likely to be involved in a transitions meeting than a young person who may need those in the future, but the family has not got there yet.*

(Social Services Manager)

### **Inappropriate scheduling**

Respondents often seemed very divided over the effectiveness of arrangements for holding transition reviews. Head teachers tended to see themselves as doing their utmost to be flexible and thoughtful in the scheduling of reviews:

*We timetable perhaps six a day, and that enables people to stay for the day and see as many as possible. We rely on them telling us the dates that are best for them, and then we set the dates around them. We get the dates, probably the year before, so we can schedule the reviews and get invitations out quite early.*

However, those invited from outside of the school did not always seem to appreciate this effort.

*We know that reviews are not particularly well planned in people's diaries...you get fairly short notice.*

(Learning Disability Manager)

*The main problem for me is that the reviews are not co-ordinated. Yesterday afternoon and next Tuesday afternoon, I am supposed to be in four places at once, and there are reviews going on in four separate establishments for which I am the link... Effectively schools make their own arrangements, if you can make it you can come, if you can't, tough.*

(Connexions PA)

### **Inter-authority wrangling**

In one case where a young man had spent his entire schooling in an out-of-authority placement, there was disagreement as to which authority should even be sending representatives to the review meeting – a classic case of discontinuity of care.

*One place was saying because he had his education in 'X' he was their responsibility, but 'X' was saying because he lived in 'Y' it was their responsibility. He was 18 and Careers said they didn't know which authority had to see him.*

(Parent)

In one authority the situation seemed to have been reached where the poor attendance for review meetings had created a vicious circle in which the meetings themselves had become downgraded in significance. According to a Strategic Manager in Children's Services:

*We've had amazing conversations with the schools for children with severe learning disabilities who would report that they had Year 9 transition meetings scheduled for 20 minutes each because nobody came. Schools were saying they didn't want to allocate an hour and be sitting there for 40 minutes with nothing to do.*

This is a significant illustration of how the transition review can be downgraded as a priority in the teeth of all of legislation and guidance to the contrary.

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### **5.3.2 Vertical inter-professional continuity**

The issues relating to the links between social care professionals for children and adults has already been noted. A further issue that was very significant for carers was that of changing access to healthcare professionals. It has often been difficult for people with learning disabilities to maintain and improve their health. Several factors may lie behind this: living lives not conducive to good health; insufficient knowledgeable support; poor access to healthcare and an inadequate response from service providers (Elliott et al, 2003). The idea of a Health Action Plan (HAP) comes from the *Valuing People* White Paper (Department of Health, 2001a) as a way of detailing the actions needed to maintain and improve the health of an individual – a mechanism to link the individual and the range of services and support they need. The White Paper gives specific targets for implementing HAPs:

- all people with a learning disability to have a HAP by June 2005;
- all Partnership Boards to have agreed a framework for the introduction of HAPs, and to have ensured that there are clearly identified health facilitators for all people with a learning disability by June 2003.

The White Paper also says;

- all people with a learning disability should be registered with a GP by June 2004;
- GPs should identify all people with learning disabilities registered with their practice by June 2004.

Subsequent guidance on HAPs from the Department of Health (2002d) suggests that it is useful to see health facilitation as a role rather than necessarily a specific post, and one which has two dimensions – case work to help people access mainstream services, and development work within mainstream services to help all parts of the NHS to develop the necessary skills. It is further suggested that health action planning should be informed by five principles:

- support the White Paper's values of rights, independence, choice and inclusion;
- have individual plans and strategic actions to support and sustain their development;
- address both individual and societal influences on the health of people with learning disabilities;
- share responsibility with each person and agency playing a role appropriate to their skills and experiences;
- support the mainstream agenda and the drive to reduce health inequalities.

There are some specific connections between HAPs and the transition from adolescence to young adulthood. HAP guidance identifies several health-related transition difficulties:

- lack of a systematic individualised planning process;
- problems with the process of transition, such as moving within or between healthcare trusts;

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- problems with the availability, quality and frequency of healthcare provision available in adulthood;
- wider health-related issues which may impact adversely on other aspects of a successful transition, such as lack of accessibility of college or employment environments.

*Valuing People* identified the transition from secondary education as one of the priority stages when HAPs should be offered and reviewed. The later guidance states that HAPs will normally begin with transition planning around the age of 14, so that the system is in place over the period of the transition. The main vehicle for considering health needs is the transition planning process led by the school. The revised *Special Educational Needs: Code of Practice* (Department of Education and Skills, 2001), for example, states that:

*Health professionals involved in the management and care of the young person should provide advice towards transition plans in writing and, wherever possible, should attend the annual review meeting in Year 9. They should advise on the services that are likely to be required and should discuss arrangements for transfer to adult health care services with the young person, their parents and their GP. They should facilitate any referrals on transfers of records which may be necessary, subject to the informed consent of the young person and parents, and should liaise with the Connexions Service as appropriate.*

(section 9.60)

Partnership Boards, Connexions and other agencies are accordingly urged to check on the following range of issues:

- is there a system locally to ensure that all young people with learning disabilities have a comprehensive transition plan which addresses their health needs?
- is there an adequate system for identifying the numbers of young people with significant health needs in advance of the move to adult services, including those young people currently placed out of area?
- on the basis of the above information, is it possible to identify or develop the resources that will be required?
- is there a shared assessment framework in use locally to avoid young people with learning disabilities and their families going through multiple assessments for different health or social care needs and services?
- is there a satisfactory process for ensuring the effective involvement of primary, secondary and tertiary (where appropriate) healthcare professionals in transition planning meetings?
- is there any system locally for developing 'hand-held records' for young people with learning disabilities and their families to take with them to adult services?
- is accessible information available for young people with learning disabilities and their families on relevant health promotion issues, including sexuality and personal relationships and health screening?

Heslop *et al.* (2001) could find little evidence that the move from paediatric health services to adult health services was handled well at transition. Over a half of parents said the transfer had not been dealt with at all during transition planning, with only 18% thinking it had been covered well. There

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are two major aspects to this – the handover itself, and the quality of service received.

The transition to adult health services is described by Heslop *et al.* as 'on the whole a rather abrupt affair' (Heslop *et al.*, 2001, p.65), with the young person and their parents typically being told at one visit that their next appointment would be with an adult team that they had not yet met. However, it was often far from clear when this transition – whether abrupt or not – even had to be made. In one of our sites:

*There seems to be a lot of confusion on the part of parents about who is responsible for their child's health during transition. You get some paediatricians who are very flexible and will hang on to the youngsters and provide some continuity, but a lot of others don't have that involvement.*

As in the case of social care, the age at which any such handover should take place was not always clear. In one of our localities, for example, services for children with learning disabilities were handled by the Child and Adolescent Mental Health team, who only accepted referrals up to the age of 16, whereas adult learning disability services did not commence until 18 or even 19. In the same locality, the main transition that concerned the two learning disability nurses was that from primary to secondary school, rather than from children's to adult services – another reminder that the very concept of transition is many-sided.

For parents, the abruptness of the service loss was exacerbated by the loss of the school as a 'one stop shop' for healthcare:

*When you are at school, everything happens there. Your paediatrician will probably come into school, the [occupational therapist], physio, nurses. When you come out of school you do not have that health back up, you have to do things through your GP.*

(Social Services Manager)

Where the relationship between the family and the GP is good – and particularly where it is also of long duration – the access to healthcare may still be effective:

*My GP is really good, he's known Paul since he was born.*

*Our GP has come up trumps, he's been really good. Jim has had a few problems lately, and the GP has approached different specialists and got him sorted out.*

*She has had the same GPs from being a week old. When I said she would be moving out of the district and would he still be her GP he said he would keep her even though he shouldn't. We've been lucky that way.*

(Parents)

Equally positively, one locality placed its children's disability social work team with the consultant community paediatrician, specialist health visitor and associated professionals such as physiotherapists and speech and language therapists. This was said to be 'working well but could work an awful lot better if there was one person managing the team'. Elsewhere it was suggested that a linking role was needed with some specialist learning disability health professionals working between learning disability and mainstream health services – a finding similar to that of Giraud-Saunders *et al.* (2003) in a separate study.

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However, the more fundamental issue facing young people and their parents was the reduced nature and range of health support available after the transition from 'childhood'. Regular and ongoing appointments with known health professionals ceased, to be replaced by an injunction to contact services as and when help was needed. Even this more uncertain system can only function where comparable adult services are available, and this was often not the case, with shortages of occupational therapists, speech therapists, clinical psychologists and psychiatrists. Where young people have a dual diagnosis of learning disability and mental health needs, or complex health needs, local partnership arrangements may be inadequate to the task. The Social Services Inspectorate national inspection reported that 'common files were rare and integrated team working was only just beginning in most areas' (Social Services Inspectorate, 2003, para 6.4).

### **5.3.3 Lead agency**

Transition involves such a wide range of stakeholders that two of the alternatives to partnership working – structural integration and lead agency status – were difficult to adopt. Hence the emphasis tended to be upon partnership working, and it was not always easy to see clear patterns of responsibility and accountability for ensuring that an effective transition was delivered. Several potential vehicles are identifiable.

#### ***Joint Investment Plans and Health Act flexibilities***

Joint Investment Plans (JIPs) and Health Act flexibilities do not specifically arise out of the *Valuing People* White Paper but are contemporaneous with it. By the end of April 2001 all relevant local authorities, together with their partner agencies, were required to have in place a JIP for learning disability covering the years 2001/2002–2003/2004. Despite the availability of JIP General Guidance and a Learning Disability JIP Workbook, the first plans had to be produced prior to the publication of *Valuing People* and may not have fully addressed the new requirements. In principle, the Learning Disability JIP could provide the right sort of vehicle for pulling the contributions of the relevant partners together, but early evidence is unconvincing.

An evaluation of the first round of the JIPs (Swift, 2002) reported that just under half of the areas had what was termed 'narrow' stakeholder partnerships, where the strategic decision-making was limited to local-authority departments and the NHS. The same study reveals 'serious shortcomings' in the availability of information about the client group – integrated client databases or registers were a rarity, and even where they existed were incapable of supporting a person-centred approach to planning. In our study, the JIP was not portrayed as a document that was guiding local developments in a rational and coherent manner, and was rarely mentioned during fieldwork interviews. In the case of transition, the range of stakeholders that would need to sign up to an effective programme is greater than could be found in Swift's narrow partnerships. Overall, the Learning Disability JIP has yet to become the key strategic document that shapes service development and practice across a local area.

The flexibilities – pooled budgets, lead commissioning and integrated provider – introduced by the Health Act 1999 provide the framework within which



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Learning Disability Partnership Boards are required to operate. The Government expects all agencies involved in the Partnership Board to show in their updated JIPs that they have fully considered how to use the Health Act flexibilities to underpin effective partnership working. The White Paper warns that 'evidence of failings in partnership arrangements will be taken into account in determining the allocation of the new Learning Disability Development Fund' but it is not clear how 'failings' will be judged or by whom. Early evidence on use of the flexibilities (Hudson *et al.*, 2002) suggests that shifts in service output take time to deliver, and that much of the early effort tends to secure symbolic rather than 'real' gains for users and carers.

The Social Services Inspectorate national inspection (Social Services Inspectorate, 2003) reported that most of the authorities covered by the inspection had not yet used the flexibilities, and that many councils were dogged by pressure on budgets and a history of demarcation disputes with NHS agencies. In our study, all of the localities were using the new powers or were planning to do so.

One of the localities was among the first to notify the Department of Health of its intention to use the flexibilities of Section 31, but in reality achievements remained limited:

*We have got an integrated service and pooled budgets – yet we haven't, for two reasons. First, we haven't signed anything legally, and secondly, although we have co-located people we haven't got protocols worked out, and we are still duplicating tasks.*

(Social Services Manager)

*The talk is of pooled budgets, but the lawyers are crawling all over cases. The arrangements underpinning the pooled budgets are not robust enough.*

(NHS Manager)

In a different locality, work on a pooled budget was said to be about to get underway, but here also there was concern about 'getting in too deep':

*We are going to create a pooled budget for learning disability teams, but not for provision. It's a budget for the cost of the staff. We are starting simple. What we don't want to do is start off with something bigger than we can handle at this point in our development.*

(Social Services Manager)

In our third locality a more structured approach was getting underway, with a pooled budget for adult services agreed between social services and the PCT, but children's services remained untouched by this sort of approach. The pooled budget is managed by an Integrated Commissioning Board, which takes advice from the Learning Disability Partnership Board. A senior local-authority officer commented on the relevance of this for transition:

*Traditionally what we've done is that the children come through the system, and at points in the year there are individual discussions about resources. At the end of the year we might find we are half a million pounds short or whatever, and we have to find a way of managing that and rolling it over to the next year. This year, for the first time, the transitions co-ordinator is providing us with information for our business-planning cycle so that we can plan for the size of our pooled budget. At least we are identifying that early in the year, and that will help us to make better decisions.*

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Overall, then, relatively little use was being made of the Health Act flexibilities. The reasons behind this are in line with the findings of Hudson *et al.* (2002) that unless there is a high level of trust among the key partners, then engagement will be limited and symbolic. In the case of transition, the range of partners goes beyond the agencies legally entitled to participate in a Section 31 partnership, but even among the legal parties across local government and health, there seems an insufficiently robust relationship to use any of the three flexibilities for transition-related purposes.

### **Learning Disability Partnership Boards**

Learning Disability Partnership Boards were established in all local-authority areas in October 2001, and are responsible for those elements of the Government's proposals that relate to services for adults with learning disabilities. Services for disabled children will continue to be addressed through children's services planning structures, and this raises an important intersection in the case of transition from adolescence to young adulthood. The board will operate within the overall framework provided by LSPs, which is consistent with the mainstream service focus underpinning *Valuing People*. The Chief Executive of the local council has responsibility for ensuring the board is in place, and membership to reflect its wide remit is expected to include senior representatives from social services, health bodies, education, housing, community development, leisure, independent providers and the employment service, as well as representatives of users and carers.

Learning Disability Partnership Boards are not statutory bodies and therefore cannot appoint staff or hold budgets, but are still capable of being important partnership forums. Department of Health guidance (Department of Health, 2002c) suggests several reasons for this. The boards have been given a number of important roles including developing and implementing the JIP, overseeing inter-agency planning and commissioning, ensuring use of the Health Act flexibilities, and ensuring arrangements are in place to achieve a smooth transition to adult life for young people. The guidance notes that whereas individual organisations *could* take unilateral action, this 'will be viewed negatively by the Department of Health in its performance management and monitoring role', and there may be implications for access to the Learning Disability Development Fund. Agencies are accordingly advised that 'an authority should not agree a policy or initiative that does not have Partnership Board support' (ibid, Section 4).

Further advice on making Learning Disability Partnership Boards work is given in the guidance. In particular it is urged that members have the necessary authority to state their organisation's position and commit their organisation to action, 'otherwise the Board will become a talking shop' – a reason for involving elected members. *Valuing People* requires the appointment of a senior person to take forward the agenda on behalf of the board, and it is suggested that this person should view their responsibility as being to the board rather than their employing organisation. Indeed, it is suggested that this should be a Partnership Manager having real responsibility for the main areas of service planning and delivery. Specifically, the board should appoint a Transition Champion for taking forward the transition agenda.

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We did not do intensive work on the boards, but it was an issue raised in our fieldwork interviews. Overall, there was little evidence to suggest that the boards in our sites are working effectively in general, or specifically in relation to transition. The most positive comment was one suggesting that the board was 'on the right lines but still had some way to go'. Others were more openly critical on several grounds. In terms of operational focus:

*The board is the vehicle for promoting Section 31 and things like that, but it tends to be weighed down by operational stuff and family concerns. It needs to change, it needs to have an impact on what's going to happen.*

(nurse representative on board)

However, in one of our sites, a clearer attempt had been made to tie in the Partnership Board to the decision-making and resource-allocating process:

*I see the Partnership Boards and the Integrated Commissioning Boards as the centre of gravity. Commissioning Boards hold the money, Partnership Boards come forward with the ideas, and that's why they have the task groups attached to them.*

Where there was no such clarity on where the board fitted into the wider system, interest could dwindle. In one such locality, a failure on the part of the board to manage the work of its sub-groups was seen as damaging to the reputation of the board:

*The sub-groups don't feed back well to the board, and the board does not manage the sub-groups well. It is run as a board and sadly most people are bored.*

(Social Services Team Manager)

### **Membership issues**

Despite an ostensibly wide-ranging membership, some gaps were identified. In one locality the absence of representation from special schools was felt to be 'a big gap'. Elsewhere, a broader issue of representation of children and young people was felt to be missing on an avowedly adult-oriented board. Other apparent absentees from the board table were LSCs and representatives from the employment services. On the other hand, the boards could still be perceived as too big to be effective:

*The number of people attending must have been over 20 and you couldn't really take any action forward; it was more of a talking shop.*

(Connexions Area Manager)

### **Sporadic attendance**

Wide-ranging membership is not the same as regular attendance, and some parties were sometimes noticeable by their absence:

*It would be fair to say that input on the board from some key agencies has been sporadic; namely education, social services and education. If you don't have commitment at board level, it becomes harder to get people involved in sub-groups.*

*The schools have got seats on the Partnership Board but don't attend, which is a bit of a shame.*

*The Head of Entry Level from the college has a seat but the dates of the board clash with college holiday times so she hasn't been able to come.*

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In such circumstances it would be surprising to find that the boards had appointed a Transition Champion (as they are obliged to do) and that the champion was working effectively. Indeed, the most striking thing about the position of Transition Champion in two of our sites was how vague people were about its very existence:

*Well, I chair the Partnership Board and I suspect we haven't appointed a champion.*

*I'm not aware of a Transition Champion, but it's not beyond possibility that it's me and no one has bothered telling me.*

(Social Services Team Manager)

*I don't know if we've appointed one. If we have and I don't know about it, it's not very effective, is it?*

(Social Services Manager on Partnership Board)

*Technically there isn't a Transition Champion. It has been discussed briefly in passing by the board. Transition is so fragmented it would be difficult to find somebody who could effectively take on that role.*

(Partnership Board Member)

These are important matters for the transition issue, and suggest that the scale and complexity of transition is currently defying structural attempts to introduce coherence and purpose. Just as at operational level the co-ordinating task was sometimes being placed upon Transition Workers lacking the authority to meet it, so at strategic level the Partnership Boards did not always seem willing or capable of fulfilling the transition challenge laid upon them by *Valuing People*. In these circumstances, transition is not addressed in a holistic way. Rather, different parts and levels of the system may come together on an *ad hoc* basis, typically reacting to a crisis. The key feature of transition seems to be discontinuity rather than continuity. It was precisely to address this problem that the Connexions Service was created.

### **Connexions partnerships**

The other new partner in the inter-agency machinery is the Connexions Service. Unlike other parts of the system, Connexions has a specific remit to assist all young people with the transition to adulthood. It is a new service for all young people aged 13–19 (although in the case of learning disability it may continue up to the age of 25) that aims to increase participation in learning 'to ensure that all young people have the opportunity to learn the skills they need to make a success of their adult lives...guiding and supporting all young people through their teenage years and in the transition to adulthood and working life'. It aims to do this by providing 'a coherent, appropriate, high-quality pathway to adult and working life for every young person, with targeted systems of support for those who need it, when they need it, linking all aspects of young people's lives' (Department for Education and Employment, 2000).

The service is based on the following key principles, all of which are consistent with the approach embodied in *Valuing People*:

- raising aspirations,
- meeting individual needs,

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- taking account of the views of young people, including those from black and minority ethnic groups and those who are hard to reach,
- inclusion – in the mainstream rather than at the margins,
- partnership with a variety of agencies to achieve shared aims,
- community involvement and neighbourhood renewal,
- extending opportunity and equality of opportunity,
- evidence-based practice.

A series of pilots started in 2000, with the first 16 services being launched from April 2001 onwards, and a second phase from April 2002. There are three elements to the organisational structure of the Connexions Service, as follows.

- The National Unit is part of Department of Education and Skills and has responsibility for Connexions Service policy, establishing a Grant Agreement for Connexions Partnerships for development and delivery of service, monitoring performance and improving quality.
- Connexions Service Partnerships are the strategic bodies responsible for the development and delivery of the service in their area, and will share the same boundaries as the 47 LSCs. They decide how Local Management Committees will operate, ensure the service is delivered at a local level and contract for local provision and specialist services.
- Local Management Committees, which should be chaired by local-authority Chief Executives or someone of comparable status, are responsible for the day-to-day operational management of the Connexions Service at the local level based upon local-authority boundaries.

The Connexions Service is not an entirely new creation, since part of its remit involves taking over responsibility for careers provision and bringing together previously separate services and agencies such as Youth Services, Education Social Work and some voluntary-sector and community provision. At operational level, the heart of the new service will be the Connexions PAs who will work with the full range of appropriate partners – their role will be examined in the next section.

A Connexions Partnership has the task of trying to build relationships with a plethora of organisations. Guidance on the relationship between Connexions and social services (Department of Health/Connexions, 2001) states that the service will develop a 'cross-cutting strategy', and that:

*by developing the service across organisational boundaries, Connexions will help to develop consistency in the support young people receive, based on a shared understanding of their needs, and will help to strengthen the links between agencies.*

(ibid, para 2.1)

The service therefore seems to be best understood as playing an integrating role among existing agencies, rather than providing something different or additional:

*The Connexions Service should not duplicate or replace the work of existing agencies, but should build on and work closely with existing services to ensure that resources are used to best effect.*

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(Section 5)

Supplementary guidance on the role of Connexions in the case of young people with a learning disability (Connexions, 2001) emphasises that young people must not 'fall through the gaps between services', and states that 'Partnerships will draw up local statements of cooperation' in relation to services for young people with learning disabilities. The key partners will be LSCs, the Employment Service and social services. In the case of LSCs, Connexions Partnerships are expected to forge close relationships to ensure links with training provision and the labour market. It is the LSCs that will have the task of ensuring that provision exists to meet the needs of young people with a learning disability who have been assessed by the Connexions PAs. The main relationship in the Employment Service is expected to be with the network of Disability Employment Advisers who work as part of a local Disability Service Team to help job seekers with more complex barriers to employment. Finally, contacts are anticipated with social services and the NHS over such matters as individual assessments, planning and provision of services, JIPs and use of mainstream leisure and culture activities.

In pursuing these relationships it is further suggested that Local Liaison Groups be established, membership of which could include the Connexions Service, Employment Service Disability Services, local further education/higher education suppliers, voluntary organisations, employers and others. These groups are urged to work jointly on a wide range of tasks relating to learning disability, including:

- the sharing of information on policies, practices and procedures with a view to their alignment;
- collaboration on projects such as information which will help the transition from school to work;
- discussing, developing and implementing ways of improving services;
- reviewing joint agreements on an annual basis;
- keeping data on destinations of young people with learning disabilities to ensure that individuals and groups are not falling between services.

This all adds up to a very demanding partnership remit, and it is not yet clear how effectively it can be addressed. One way of inducing partnerships is to link resource allocation to evidence of effective partnership working, but the funding base of Connexions does not easily provide this. Funding from the various partners will not be transferred to Connexions or any other joint body, but is seen as:

*part of the overall resources that are available at a local level... Partners are not expected to transfer staff or money to the Connexions Partnership...rather they are asked to identify the work that they do that will also help to deliver the goals of the Connexions Service, and to make sure this is coordinated effectively.*

(Department of Health/Connexions, 2001, para 4.1)

The capacity of the Connexions Partnerships to undertake this partnership remit remains unclear. Several issues are emerging from wider literature and our own fieldwork.

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### **Impact of limited funding**

It has been reported that many Chief Executives of Connexions branches have expressed concerns about the resource implications of delivering the service to young people with learning difficulties. The responsibilities of Connexions PAs are viewed as very resource-intensive, with PAs struggling to meet their responsibilities and to find the time to attend review meetings. In one of our localities, for example, there was a complement of 25 PAs – about a third more than in the budget of the previous careers service – but there was still considerable pressure on resources. Previous perceptions of what the service might be able to do had been scaled down:

*You had all the talk about a universal service which wasn't particularly helpful, especially as there was no attempt to define what a universal service might be. Schools thought there would be hundreds of PAs allocated to them, and that they would recruit and manage them. But they are now simply being told who the PAs for the school will be.*

(Local Connexions Manager)

*Connexions has become a victim of the heightened expectations coming out of national guidance. I think a lot of people are going to be disappointed, and we will have to be increasingly clear about what we can and can't do.*

(Connexions Service Manager)

The funding issue – or to be more precise the unavailability of new funding – also has an impact at operational level, where Connexions PAs are reluctant to heighten expectations that cannot be met:

*We have to be very careful about recommending to young people and their parents when we are giving them advice, because at the end of the day we don't fund any services. We offer advice and information. We have an overview of what's going on in different agencies, but it all comes back to the fact that we are not a funding agency.*

(Connexions PA)

### **Role confusion and role tension**

Issues arose at the national, local and operational levels. Nationally, there was still a problem about throwing off the service and the cultural legacy of the careers-service role. It was said that many staff in schools and colleges wanted no less than they had previously had from the careers service:

*There is this massive pressure for Connexions to continue to do what the careers service did, yet it is also expected to be much more accessible to the community than was the case with the careers service.*

(Connexions Manager)

This was also impacting upon the way PAs felt able to take on a new and wider role:

*To be honest, most people are just going about their business doing what they always did, and hoping nothing else is going to change.*

(Connexions PA)

There were two other national factors affecting the pace of change. First, the location of Connexions in central government. According to one local manager:

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*Connexions is attempting to work across at national level something like half a dozen different government departments to bring some consistency of approach. We deliberately do not have a 'home' department, rather the Connexions Central Unit was set up to pull all those departments together. This is much more difficult to do than you might imagine. There is still inconsistency at national level coming from different departments putting a spin on things. We are accustomed to saying OK, your department is doing that, but are you aware of the approach in another department?'*

This difficulty is reflected in the voluminous amount of guidance published by the Connexions Service National Unit, much of it on children with learning disabilities.

*We have had national documents coming out telling us about Connexions for something like 3 years. Many of them are inconsistent with each other – what you are told in one document may well be contradicted in another.*

(Local manager)

The situation is further complicated where several different government departments are issuing guidance on similar themes. One Connexions Manager found this a source of confusion and frustration:

*Some stuff comes out of the Department of Health, other stuff from Department of Education and Skills. I don't know how well they get on and talk to each other. And of course we have LSC at Coventry as well. So joint working needs to happen up there as well as down here.*

Connexions staff at the local level had to reconcile these different demands and obligations as best they could. At local strategic level, one manager bemoaned the common confusion being made between the Connexions Service and the Connexions strategy:

*Often the term Connexions Partnership is very confusingly used in the national documentation, because they use it on some occasions to mean the Connexions Service and on others to mean the Connexions strategy, which is the pulling together of all the local partners. It has sometimes led to an assumption that the Connexions Service is there to do everything with young people, rather than being an umbrella. The Connexions Service is not the Connexions strategy, it is just one of a number of players out there.*

One way of making sense of this implementation dilemma was to be selective and flexible in interpreting guidance.

*It's unrealistic to deliver on central guidance at the front line. Connexions Service National Unit bring out national guidelines, it is then interpreted at local level, and then again by your local management committee. Some enforce rules to the letter, others take a much more lenient approach.*

(PA Team Manager)

All of this affects the extent to which Connexions can fulfil its local co-ordinating role. Nationally, the Ofsted inspection of the first year of Connexions Partnerships (Ofsted, 2001) has shed some wider light. It is reported that:

- in two-thirds of the partnerships, some key partners such as the youth service, employers and training providers were not appropriately represented on the boards and at Local Management Committee level;
- the large majority of partnerships had not made clear the nature of the Connexions Service that they intended to provide, and how this related to the roles and responsibilities of partner organisations;



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- agreements, protocols and procedures for joint working were under-developed, and as a result tensions remained in the relationships with partners such as the youth service, social services, schools and colleges, which inhibited their full participation;
- partnerships were unable to judge the impact of the work with their partners and their overall effectiveness.

Since the publication of *Valuing People* and the availability of the Health Act flexibilities, the creation of Children's Trusts has created yet another partnership structure with the potential to address transition issues. At a minimum, Children's Trusts should include social services, education and health, which covers three of the most crucial transition parties. In the view of a Connexions Manager, this seemed a sensible strategy:

*What I still tend to find is that if it's a meeting that social services has organised, we will be there with them; if education has organised it, we will be there with education. But you very rarely get a meeting where they are both there. It has always amazed me that people in a town hall would communicate through us about somebody down a corridor. Why should a social worker ring me about an education file? Hopefully Children's Trusts will drive that one through.*

One of our sites had successfully applied for Children's Trust status. However, there were mixed views about the desirability of Children's Trusts in relation to transition:

*It could be a huge advantage in some ways, but if services for children are taken out separately, and the connection to adult services is not properly made, you could have services delivered from a Children's Trust that are very different to those people expect as they go into adulthood.*

(Social Services Manager)

More broadly, there is the fear expressed by one manager in adult social care: 'the importance of *Valuing People* has yet to be made clear to those people who are involved in children's planning processes.'

### **5.4 Personal professional continuity**

Two potential sources of personal professional continuity seem to be available, both of them relatively new phenomena – the new breed of Connexions PAs and dedicated Transition Workers, normally appointed within adult social care. The role of both is unclear, as is the relationship between them.

#### **5.4.1 The PA system**

Evidence from the USA stresses the importance of 'transition care management'. Designation of a person responsible for transition to facilitate care management, advocacy and inter-agency co-operation was found to give assurances that someone would consider issues beyond their own particular system, and would feel responsible for the student during the transition from one setting to another (Aune, 1991). In England, the only nationally planned equivalent to this role is the emerging breed of Connexions PAs whose sole focus is the years of transition between adolescence and young adulthood. Their job will be to ensure that the needs of individual young people are met

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so that they are able and motivated to engage in education, training and work opportunities. Their work has two dimensions: direct work and so-called brokerage work.

### **Direct work**

Direct, hands-on work may be with both young people and their parents. They will provide general advice and support to most young people and, where needed, intensive and sustained support for those with severe barriers to learning – young people with learning disabilities are identified as requiring particular support. This will be a one-to-one relationship over a sustained period, possibly up to the age of 25. With the consent of the young person, the PA may also work with parents and carers.

### **Brokerage work**

It is in undertaking the brokerage role that inter-professional partnerships become prominent. Connexions guidance (Department of Health/Connexions, 2001) identifies three broad levels of service according to young people's needs:

- information, advice, guidance and review of career/learning/employment and personal development choices;
- in-depth guidance and help for those at risk of disengaging;
- intensive sustained support for those with multiple problems.

It goes on to state that for those facing multiple problems:

*...the role of the personal adviser will be to broker access to specialist support as necessary, and ensure a co-ordinated approach to supporting the young person across agencies.*

(ibid, para 2.4)

Further guidance on the role of Connexions in relation to learning disability (Connexions, 2001), sets out an ambitious brokerage remit for PAs:

- influencing LSCs and other providers in the planning and evaluation of their provision – LSCs should have a named official to whom the PA should relate;
- consideration of the availability of people to work with students;
- consideration of the availability of 'follow-on' provision;
- consideration of provision by social services, the Employment Service, voluntary-sector agencies and transport agencies;
- arrangements for progression towards the individual's post-learning goals, including employment, supported employment and independent living;
- regular contact with head teachers, special educational needs co-ordinators in schools and youth workers;
- arrange a case conference for those who make the transition after their 20th birthday, to agree what the support needs are, and which organisation should lead.

In undertaking these tasks, the Connexions Service is told that it should not duplicate or replace the work of existing agencies; rather it should build on

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and work closely with existing services to ensure that resources are used to best effect (Department of Health/Connexions, 2001). This is quite a tall order, and there is likely to be some organisational and professional jostling for position. In an early review of one of the Connexions pilot schemes, Grove (2001) found general agreement that the PA was someone who 'was there' for students and carers, and students said they liked the idea of having an independent person with whom they could discuss their plan and ambitions. Supported employment agencies were also keen that the PA should bring in a vocational focus that is typically missing from schools. However, it is noted that 'being there' for students has the potential to bring the PA into conflict with the school and perhaps the carers. Those parents speaking positively about their experiences with a PA tended to highlight the brokerage role rather than the direct work:

*Connexions have been really good helping me fill forms in for college, especially applying for funding. They were there on the end of a phone and gave me the hope that he could achieve residential college, that it wasn't just a pipe dream.*

(Parent)

It may be difficult to avoid stepping on other professional toes. Grove (2001) notes that most, if not all, of the functions that the PA was trying to carry out were (or have been) done by other professionals, leaving the PA to find the bits the others do not have time to do – hardly the overarching co-ordinating role envisaged for PAs. The issue of professional status is also significant. The study found that most PAs were not even regarded as 'professionals', and had little credibility beyond that which they could secure from their personal qualities – a position that was exacerbated where they did not have the tools and space within the school to do their job.

As the service develops, the training and experience of PAs will be crucial to their effectiveness and professional respectability. In the field of learning disability they will need a good understanding of such issues as:

- the education system as it applies to these young people,
- awareness of child-protection issues and legislation,
- training in basic counselling and mediation,
- training in alternative systems of communication,
- skills training in vocational profiling,
- employer and employment awareness,
- intersection of employment and social security,
- independent- and supported-living options,
- wider issues around community integration.

It remains to be seen whether the current training prepares PAs effectively along these lines, and the position is further complicated by the possibility that such specialist training could lead to professional isolation and limited career development within the Connexions Service. It was reported in *The Guardian* (22 October 2002, p.7) that doubts were being expressed about the expertise of PAs responsible for assessing the wide needs of young people. Although PAs receive only basic counselling training, they are expected to cover a range of complex issues and conditions, including special needs, mental health, physical or sexual abuse and substance misuse. A separate

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report (*Community Care*, 12 November 2002, p.5) revealed that lack of awareness of learning difficulties was leading some PAs to have very low expectations of some people's potential work or training abilities.

More positively, Rowland-Crosby *et al.* (2002) suggested that the majority of young people in their survey saw Connexions in a very positive light: 'they had not had access to support like this before, and feel valued through the whole process of being able to sit down and talk about the future with someone' (Rowland-Crosby *et al.* (2002, p.13). Similarly, the Ofsted inspection (Ofsted, 2001) felt able to conclude that the role of the PA was 'developing well', but followed this judgement with some rather stern qualifications:

*Some PAs do not yet have the breadth of skills and knowledge to perform the wider role needed in an integrated support service. Partnerships have yet to put into place sufficiently robust arrangements and procedures for needs assessment, planning, recording, referral and tracking to ensure the work of the PA is effective. There is a lack of clarity and understanding about the role and deployment of the PA across many partnerships and within schools. In over two thirds of the partnerships, the arrangements for the line management and professional supervision of PAs are unsatisfactory, and insufficient to support them in developing their role and a coherent approach to the services they provide.*

(ibid, p.5)

### **Inadequate expertise**

PAs may be directly employed by the Connexions Service, seconded to the service or remain within their existing professional context working under a Partnership Agreement with the service. In most of the pilot sites, the service was led by the privatised career service, which may not be well equipped for the challenge of learning disability. One PA who specialised in special needs expressed a sense of professional isolation:

*I think there is a basic lack of understanding strategically about the needs of young people with special needs. There is nobody I know of up there who has a solid special-needs background, interest or title. There is nowhere to feed into.*

For some parents, the lack of specialisation of the PA was a source of difficulty:

*The Connexions worker came and said 'I'll be honest with you, I can't make head nor tail of what your son is trying to tell me'. I thought, well, thank you for being honest with me, but you are in a job where you are working with special needs and you have come to tell me you can't understand what he is saying! Well, why have you bothered coming? She never got in touch again.*

(Parent)

### **Caseload pressures**

The Ofsted inspection (Ofsted, 2001) noted the difficulty caused by unduly high caseloads:

*In many areas, the caseloads of the PAs are uneven and there is uncertainty about how needs are to be prioritised and met in the future. Some PAs working with young people with multiple difficulties have a caseload of 30 such young people... Some headteachers expected a higher allocation and are unsure of the rationale for deployment of PAs.*

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(ibid, para 66)

In our localities, the core staff from which PAs were drawn was the former careers service, but there had been recruitment drives to supplement this with people from other backgrounds and with other expertise, including social services. For one senior social services manager this was not a solution, but a further problem:

*I think PAs do a very good general helpline-type information service, but to think that they will be able to provide a PA for all children in areas that need them is just unrealistic. What will happen is they will start to recruit from the staff groups where we are already stretched in social services, for instance, so maybe they will take over in the end because we won't be able to do it.*

### **Generic versus specialist PAs**

The distinction between the universal PA and the targeted or intensive PA is of particular relevance in the case of learning disability. The latter refers to the provision of support for young people with specific or multiple needs who require additional and more focused support than is normally the case. The Ofsted inspection (Ofsted, 2001) found that in some settings the universal PAs still saw themselves only as careers advisers, and referred to the targeted PAs as the Connexions PAs. PAs could also find this a confusing situation:

*I'm the only one who has an entirely special needs caseload, but as far as I'm concerned I'm still just qualified as a careers adviser and not a lot else. We are being asked to work in a very, very different way, and that's very difficult to get used to when the thrust of the work still has to be around offering careers education and guidance to everybody... The problem in the past has been that careers advisers have been sort of forced into doing special needs when they haven't been interested in it and haven't wanted to do it.*

In these circumstances, getting the right sort of training and support is crucial, but this seemed to be yet another area of concern. The problem was pinpointed in the Ofsted inspection (Ofsted, 2001):

*Some PAs with a careers adviser background were unable to perform successfully the wider role envisaged for a Connexions PA. They provided good careers guidance but failed to identify and follow up issues inhibiting the young person's progress. Some felt this wider role was more the responsibility of the PA providing the more intensive support; others lacked the knowledge of specialist referral agencies to assist young people with multiple needs.*

(ibid, para 45)

The formal position on training PAs did come across in our fieldwork, and it did not seem a straightforward matter. The description given by one local Connexions manager revealed a Byzantine world:

*It's incredibly complicated. You have got to get people through the PA Diploma – I probably can't say anything charitable about it, so I won't – and that is a fairly complicated, time-consuming process. It's five modules that last about 10 months at the notional rate of about a day a week. I think it's designed for people to operate generally as a Connexions PA. It would be difficult to describe it as a professional qualification because it's not competence-based. Basically, if you go in with an NVQ 4 in a relevant professional area, you come out of a PA Diploma as a Connexions PA. Some of our staff go in with an NVQ 3 in Guidance, and when they have done the Diploma they can't come out with an NVQ 4 because it's not competence-based. So they come out as a probationary PA, and exactly what we do about that we are not totally clear. There is now a new training framework that says before you do the PA Diploma, you have to*

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*do 'An Introduction to Connexions' and 'Understanding Connexions'. Having done these, in some circumstances it will mean you can be qualified without doing the rest of the Diploma. This is a problem – we have been offering staff an increment once they have completed the Diploma.*

From the perspective of a PA specialising in special-needs work, the PA Diploma was of only limited value:

*There are five assignments looking at referral, assessment, multi-agency working, audit and evaluation, and then looking at the problems that are going to be faced by setting up a new Connexions Service. Apparently this qualifies you to be this generic person. It just kind of taps the surface of everything. Special needs doesn't really fit in, it's just a case of picking it up as you go along.*

### **5.4.2 Dedicated Transition Workers**

The main response within social care to these difficulties was not to re-shape structures, but rather to appoint dedicated staff (usually just one individual) to act as a transitions co-ordinator. This sort of post may be caseload-based, or may involve more of a co-ordination role, facilitating the work of other professions and services. The Social Services Inspectorate national inspection described such appointments – typically by social services – as 'one of the keys to success' (Social Services Inspectorate, 2003, para 3.12). The *Valuing People* Support Team has published an information pack for Transition Champions (Department of Health, 2003b) that includes the following role description:

- to help the Partnership Board to understand what needs to happen to improve transition for young people aged 13–25 years;
- to raise awareness of Valuing People objective 2 (to improve the transition experience for young people and their families);
- to make sure that young people and their family members are involved in the discussions about improving transition;
- to develop strong relationships with key people from children's health, social and educational services, schools and Connexions, to influence their planning processes;
- to develop good links with key people from local colleges and adult education providers, the Learning and Skills Council, training providers, employment projects and employers;
- to co-ordinate the development of a plan to improve transition locally;
- to develop a working relationship with the board member leading person-centred planning.

This adds up to a significant 'reticulist' remit, and it is unsurprising that Transition Workers in our sample sometimes found the demands to be excessive:

*I am the only co-ordinator in all of this, so nobody else talks to anybody else. It seems a bit much to expect me to be the one who tries to pull everything together.*

In one case, the Transition Worker carried a heavy caseload, but was also expected to undertake wider co-ordinating duties, and there was recognition that this dual role was not sustainable. Elsewhere, a developmental brief was

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attached to the appointment, with no caseload responsibility until the Transition Worker had managed to institute better transition 'systems'. However, even in this latter case, the remit was to improve practices within social services, rather than to encompass all relevant inter-agency and inter-professional work. The issue of caseloads versus systems improvement marked an important variation across our sites. In the caseload-oriented site, the response to a large caseload was to consider the appointment of both a children's and adult Transition Worker; in the same site, the transitions worker felt she needed a support worker to assist her with day-to-day contact. In the systems-oriented locality, this was seen as the wrong approach:

*There is an enormous task just trying to co-ordinate within social services, and then co-ordinate what social services are doing with other agencies. In other authorities they move very quickly from planning and development – the original remit – into actually taking lots of cases. Now they find they are still dealing with the same difficulties, but no longer have time to address them.*

(Transitions worker)

Only in one of the three localities did the role of Transition Co-ordinator seem to have a clear link into a broader strategic process. Here, the co-ordinator had been in post for 2 years and was jointly funded by health and social services. Although he had a small caseload, the thrust of his work was to develop a transitions database for the Integrated Commissioning Board so that proper future planning could take place. With a clear link into the Partnership Board, this role was markedly different to elsewhere, where the defining feature seemed to be responsibility without power. However, in this particular case, plans were underway to turn this into a more hands-on role on the grounds that the initial transition-mapping process was complete, and the agencies were aware of the demand feeding through the system.

### **5.4.3 Connexions PAs and Transition Workers: professional territorialism?**

Rowland-Crosby *et al.* (2002), in an early study, noted the confusion that arose where social services had appointed Transition Workers without sharing the development with the local Connexions Service, and report only one example of a successful front-line relationship between the two agencies. Across our sites, the front-line relationship between social services and Connexions varied, and the key variable seemed to be the strength of the inter-personal relationship between the individuals concerned. In one locality a useful division of labour had been agreed:

*Connexions do practically all of the arranging of education, anything to do with funding of education, transport, anything like that, all the Learning and Skills Council applications. So far as we are concerned that's fantastic – we don't want anything to do with that.*

(Adult Social Services)

Connexions PAs are a new and emerging phenomenon, and as such they have to develop relationships with professionals from other disciplines who have a prior stake in the learning disability field. In some cases – and especially where there may be some perceived jousting for professional territory – this

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can result in a degree of inter-professional conflict. The Ofsted report (Ofsted, 2001) took an ostensibly optimistic line:

*PAs are deployed to work alongside professional staff from a wide range of institutions and agencies... Partner agencies value highly the contribution of the PAs. Their involvement enhances and extends the services and opportunities available for young people, particularly those with multiple and more complex needs.*

(Ofsted, 2001, para 58)

However, the report also notes that:

*Tensions centre on the differing interpretations of the PA role and how these should be managed. Too few teachers in colleges and schools understood the role of the PA and the relationship with other teaching staff, especially pastoral staff. The assumption that the priorities of the Connexions partnership and those of the school are the same is often a barrier to the development of provision.*

(ibid, para 62)

This is similar to the findings of Rowland-Crosby *et al.* (2002):

*There were wide-ranging levels of awareness and understanding about the role of Connexions Services. Many continued to see it as a re-branded careers service, there was a lot of confusion about age bands, and little in-depth knowledge about potential areas for working together.*

(ibid, p.14)

In our fieldwork we encountered PAs who were well connected to their fellow professionals and were held in high regard, and others who were less well placed. Whether these perceptions are reasonable or not, they do have the effect of shaping behaviour. In one locality, following the appointment of a new Connexions PA, relationships and understanding improved enormously with the Transition Worker:

*A couple of years ago there would be children with a statement who were in mainstream schools and I could easily have missed them, but now the Connexions PA spends time picking these up and deciding whether they need further support.*

(Transition Worker)

In the same locality, a previous such relationship had been characterised by low trust and respect:

*I said to Connexions that one of the young adults who is failing at college does not have a learning disability and should be a Connexions responsibility. The PA says she has visited him and feels he is lazy and doesn't want to go into education, so has passed it back to me. She has a huge remit, I'm not surprised she's trying to pass things on to me, but I find I pass very little their way. I try not to get involved because I just end up with more work.*

(Transition Worker)

In another area where relationships were much better, professional turf wars could still be a difficulty:

*If you have got a learning mentor working in a school, for example, and you also have a PA level 2 who is a non-careers background, they can't offer careers advice in school because they are not qualified to do that. So they offer other kinds of advice. Where does the learning mentor role end and begin, and*



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*where does the PA role end and begin? It's that kind of confusion that's rife through the organisation at the minute.*

(PA)

*The big issue is for other professionals to recognise that the PA should be at the centre. Everyone is very precious about their own little bit with the young person, and they don't see us as any different to the past. The school nurse still sees me as the careers advice and guidance person.*

(PA)

*If you have had a long-term social work input then the linchpin is the social worker, but for people who haven't had that then maybe Connexions would be the linchpin. But I think the role of the PA was trying to be everything, and it's just not achievable.*

(Transitions Coordinator)

For other agencies – especially adult social services – there was apparent uncertainty about the relationship between the new PAs and the newly appointed transitions officers:

*We put in some Transition Workers to improve the connections between our children's services and adult services, but since then Connexions has arrived on the scene with a clear statutory responsibility. We are at the stage of just figuring that one out. What are the PAs going to do and what is the Transition Co-ordinator going to do?*

(Children's Services Manager)

*Connexions were given a lead responsibility weren't they? One school of thought says they should take the whole lot and get on with it, just take it away from social services. If they need specialist support they can come back to us. We have not gone there at the moment. We see it as more of a working together until we have worked out who should be taking the lead.*

(Social Services Manager)

However, for one Connexions PA, if there was any confusion it was simply in the minds of other agencies:

*We are quite clear about what we should be doing – it's the other agencies that suddenly say 'Well, surely that will be a Connexions role'. Our interest is always the young person really.*

And finally, there is the issue of power. PAs are simply not well placed to pursue a co-ordinating agenda where they lack the authority to bring agencies and professionals together – in effect, a repetition of the position with Transition Co-ordinators and Learning Disability Partnership Boards. Lacking new funds to bring to the table, clear professional legitimacy or authority, PAs could do little other than work through persuasion and encouragement:

*What kind of recourse do we have if we are not happy with something that isn't being delivered? What kind of clout have we got if something is not happening that is detailed on the plan? They shrug their shoulders and say 'so what?'*

(PA)

Overall, Connexions seems to replicate the situation already described with Transition Co-ordinators and Learning Disability Partnership Boards. Strategically, Learning Disability Partnership Boards did not appear to be co-ordinating agencies effectively and, at operational level, Transition Co-ordinators lacked the authority and legitimacy to co-ordinate professionals. The new and focused alternatives in the case of transition are

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the Connexions Partnership and Connexions PAs for strategic and operational co-ordination, respectively. But here again, they have not yet shown themselves to be robust co-ordinating mechanisms. Discontinuity in transition is proving too deep-seated to respond to the substantial shifts in policy, process and machinery.

### **5.4.4 Flexibility**

#### ***Limited options: back to day care?***

The most common obstacle to flexibility was simply the lack of adult options – a paucity of choice that raises the question of transition to what? Even if it were the case that the transition process itself is sensitively and appropriately handled – and this does not seem to be the case – the effort would have little point if the post-transition options were unacceptable. The way the system copes with this reality is to focus upon what is for most young people a relatively untroubled transition from school to college, and neglect the much more problematic transition into adult life once college has ended. Gainful employment and independent living rarely surfaced as issues with any stakeholders in our fieldwork and the reality of life after college was often some form of day care.

Day services potentially address a wide range of needs that impinge upon effective transition (Clark, 2001):

- for physical care and shelter, and the prevention of deterioration of physical and mental health,
- for companionship and social stimulation,
- for rehabilitation and the teaching of new life and social skills,
- for positive experiences and new achievements,
- for promoting independence, social integration and employment.

In general, day services have not responded well to this agenda. The White Paper, *Valuing People* (Department of Health, 2001a), makes this point strongly:

*For decades, services for people with learning disabilities have been heavily reliant on large, often institutional, day centres. These have provided much needed respite for families, but have made a limited contribution to promoting social inclusion or independence for people with learning disabilities.*

(para 7.21)

Pointing out that local councils spend over £300 million a year on day services, of which more than 80% goes on over 60 000 day-centre places that often focus on large group activities, the White Paper (ibid, para 7.23) identifies four barriers standing in the way of change:

- difficulties in releasing resources tied up in buildings and staff,
- slow development of links with other services and support in the wider community,
- tension between providing respite for families and fulfilling opportunities for the person,
- slow progress in introducing person-centred approaches to planning.

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The review of evidence on day services by Simons and Watson (1999) is more direct in its critique, noting that:

*A common theme in many of the official documents relating to day services is the apparent aimlessness of a substantial swathe of provision... Assumptions about their role often appear to be implicit or barely articulated...the whole idea of a distinct entity that could be labelled as 'day services' may be a concept that is 'past its sell-by date'.*

(ibid, p.9)

Following the White Paper (Department of Health, 2001a), the new Learning Disability Partnership Boards were required to prepare day-service modernisation programmes by 31 January 2003. These should show the steps needed to achieve modernised services by 2006, with particular reference to existing large day centres, and will be expected to reflect the objective identified in the White Paper:

*To enable people with learning disabilities to lead full and purposeful lives within their community and to develop a range of friendships, activities and relationships.*

(ibid, p.76)

This is a rather different approach to the contract employment model of the traditional centres, and builds upon the notion of 'significant living without work' with the aim of maximising purposeful and rewarding activities, enhancing social contact, reducing isolation and loneliness, providing opportunities for contributing to society, and generally fostering a sense of belonging and self-esteem. The challenges of this model are identified by Clark (2001):

- more flexible in time: day services need to be available at more flexible times of day and night;
- more flexible in place: delivery in a wide range of settings in ordinary places of resort, including people's own homes;
- more responsive to individuals' requirements: a better response to the variety of individual needs and interests, avoiding prior assumptions about the progress or outcomes that individuals may attain;
- culturally and ethnically sensitive: recognition of the different expectations of the various cultural communities;
- supportive wider social integration: the fostering of roles, activities and identities outside the care context with the aim of promoting independence from the formal service.

For Simons and Watson (1999), the key to developing such a 'person-centred' approach is the availability of flexible, personal assistance provided in ordinary community settings – for young people making the transition to adulthood these could effectively be Transition Workers. It would also require a much sharper focus on partnership working – an important shift from the insularity of traditional day centres.

It has not been a key part of our research to explore the nature and effectiveness of day services, but it is important in considering transition to take account of what services and support are available once the transition bridge has been crossed. In our sites there are still some very traditional day

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services in existence. One senior manager described her shock at first visiting such a centre not long after her appointment:

*I was quite horrified. It was something like 2.30 in the afternoon on a hot sunny day, and everyone was sat in a central dining room having their cup of lemon squash. No one was outside, no one had the choice about it. They were just sitting there. It's that kind of thing we are trying to shift away from.*

Several reasons were put forward for this situation. First, the nature of provider 'culture' – it was said to be difficult to get staff to shift their traditional way of thinking, and where the choice of provider was limited, this left social care commissioners in a difficult position. Second, limited funding to develop alternative forms of support before closing existing facilities. And finally there is the issue of parental culture. The general view seemed to be that parents were of two broad types in relation to this matter. According to one parent:

*I think parents are divided into two types. First those who want a baby-sitting service from nine in the morning until four at night, usually older parents over the age of 60. Then there are the younger parents who want something better, something challenging, more stimulating. I would rather have five half days of quality than full-time rubbish.*

Almost all of the parents we spoke to were critical of what was being offered in day centres:

*I wouldn't send him to the training centre, no way. I'd rather keep him at home. I just don't agree with those places, they seem locked away to me. I know they are going out more in the community now, but I still don't agree with them.*

*I didn't want him to just go to an adult training centre, and just sit and be bored. I visited all those places and they just looked so soul-destroying.*

Another parent, while being highly critical of the day-centre regimes, remained unconvinced about the alternatives:

*They are closing down the [adult training centres] and taking them into community centres – an odd day here and an odd day there. I see them going round Morrisons, sitting in the coffee bar and things like that. Well, I don't want that for my son. He needs to keep his learning skills up otherwise it will all have been pointless.*

Overall, despite the strictures of *Valuing People* in relation to day care, the reality seems to be that traditional forms of day care remain predominant, and that this is an unpopular option with most parents and users of services

### **Direct Payments**

What the Direct Payments option proposes is securing continuity by putting budgetary control under one head – that of the user or their carer. Whereas this was raised as a serious option for something like day care, we did not hear any suggestions that the model could be transported into the transition process itself, and at the time of our fieldwork it was little mentioned by professionals or parents. One parent who was extremely dissatisfied with service availability and standard did see Direct Payments as the answer to her problems:

*When I saw the resource centre, my attitude was 'in that case he will just stay home with me every day'. I won't send him there. At the moment there is a square hole, and you get hammered into it whatever shape you are – you are*

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*going in that bloody hole. I think Direct Payments are going to make a difference. Once parents realise they can take the money for day services and buy what they want, social services are going to get the shock of their bloody lives. I'm prepared to take the money and run, and I can think of 12 [people], off the top of my head, who are thinking of doing the same.*

Another parent in the same locality also took a positive, if more cautious, line:

*If I set up my own agency that would be hard, but if I just got the money paid into the bank for the carer that would be easier. We feel that if we don't take Direct Payments we won't get anything; there's a lot of us feel that.*

However, others were clearly daunted by the prospect of Direct Payments:

*I don't really fancy the idea too much, but if I do it through social services I won't have much say as to who is employed. It's a big responsibility having to take care of someone's tax and insurance. They sent me loads of paperwork, and by the time I got on page 3 I thought I can't handle this, my head wasn't ready for dealing with it.*

The Green Paper on the 'vision for the future of social care for adults' (Department of Health, 2005) looks set to make this approach a much higher priority. Commenting on the hitherto low take-up rate of Direct Payments, the Green Paper states that:

*We would like to encourage more people to consider whether Direct Payments are right for them, particularly in groups where take-up has been low such as...young people moving to adult services.*

(ibid, para 4.23)

It is clear that this option is not confined to those with the capacity to make their own arrangements, hence increasing relevance for many of the young people and their families in this study. It goes on to say:

*We also want to consider ways of extending the benefits of Direct Payments to those currently excluded by using an agent for those without the capacity to consent, or unable to manage even with assistance. This means, for example, that a child who currently has Direct Payments managed by a parent could continue to receive Direct Payments after the age of 18, even if they have a disability so severe they cannot give consent for themselves.*

(ibid, para 4.24)

### **Person-centred plans**

In principle, the dual contributions of sensitive transition planning during school years, and the development of person-centred planning (PCP) thereafter, offers the possibility of a flexible approach to support that adjusts to the needs of the individual over time. Difficulties with the formal transition-planning process have already been noted. PCP still seemed to be at a very formative stage, and while it has the potential to be a useful way of putting young people at the heart of the transition-planning process, it had yet to be used for such a purpose in any of our sites.

Although PCP is an important dimension of the *Valuing People* changes, it is better known in social services than elsewhere, and this is a problem where the transition process is driven by a different agency – in effect, a cultural discontinuity. One social services manager spoke of a meeting with a colleague from education:

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*He was saying 'well, I'm not sure how we would fit person-centred planning into the current timetable', and I was saying 'well, it's got to fit in'. There is absolutely no reason why a school review cannot be facilitated by person-centred planning.*

Overall, at the time of our fieldwork, there was little evidence of 'flexible continuity'. Traditional services had failed to respond flexibly to new and more complex demands, and the new initiatives of Direct Payments and PCP had yet to make any impact on transition discontinuities. Again, the new Green Paper on adult social care (Department of Health, 2005) potentially heralds a fresh impetus in this respect. It notes that in order to put people at the centre of assessment and give them individual budgets they will need additional support, and accordingly proposes to explore a number of models, as follows:

- a person-centred planning facilitator to support the person to develop their own aspirations as the basis for future service developments,
- a care manager working alongside the person who may need services, to undertake the needs assessment and act as a lead professional to case manage the care package,
- a care navigator with knowledge of mainstream and specialist services, working with the person using services to develop a sustained pathway of care,
- a care broker who might help the individual formulate the care plan, negotiate funding and help organise and monitor services.

These proposals would undoubtedly receive a warm welcome from the young people and their carers in this study, but at the time of writing can be regarded as little more than relatively long-term policy goals, the future of which is uncertain. In addition, the evidence of this study is that the implementation of change is a complex area, and that the effective introduction of any of these models will be a difficult process.

### **5.5 Tendencies towards discontinuity**

The overwhelming conclusion of this research is that the transition from adolescence to young adulthood for people with a learning disability is characterised by discontinuity rather than continuity. Within this broad judgement, several issues can be identified, as follows.

#### **5.5.1 Competing priorities in learning disability**

It has not been easy to get a sense of urgency about the priority given to the transition issue in our localities. All have established some form of sub-group, but membership has tended to come from front-line practitioners, with the group chaired by an operational manager or middle manager. Whereas this has the advantage of bringing together people who have a sharp understanding of the way transition works in practice, it tends to be insufficiently powerful to initiate and sustain real change across the 'transition system'. Similarly, the appointment of Transition Co-ordinators has, in general, placed too much responsibility for systems change upon relatively junior staff.

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The priority given to learning disability in general, as well as the transition issue in particular, varied, but in general it was relatively low. In agencies other than social care, learning disability is a relatively low priority, and even in social services, there are other more pressing priorities. On the Learning Disability Partnership Boards, transition had yet to reach the top of an agenda dominated by financial constraints, the introduction of PCP, the re-shaping of day services and, in some cases, the closure of long-stay institutions.

Transition working and planning is in competition with other local priorities. Although the issue is highlighted as one of the key objectives of *Valuing People*, the White Paper involves no legally binding duty to implement proposals and meet objectives. Also, there has been little new money made available to meet the objectives of *Valuing People* other than the annual Learning Disability Development Fund that stands at around £20 million. Although there may well be room for improvement in expending the current £4 billion per annum devoted to learning disability services, greater independence does not come cheap. As Walker and Walker (1998) argue, the lives of people with learning disabilities are restricted because it is cheaper for services to ignore those not in crisis, than to intervene.

These concerns seem to have been echoed in a report from the Learning Disability Task Force (2004), which suggested that only 0.43% of the £4 billion was being spent on implementing the principles of *Valuing People*. The report argues that national performance indicators have continued to measure pre-Valuing People models of care, rather than focus upon activities such as PCP and Direct Payments. Indeed, it was further reported (*The Guardian*, 30 July 2003, p.9) that even the ostensibly ring-fenced £20 million in the Learning Disability Development Fund was being raided and used for purposes other than learning disability. All of these concerns were further reflected in the assessment of progress on *Valuing People* undertaken by the Commission for Social Care Inspection (2004), which found common problems across the country, including a lack of choice in services, lack of specialist staff and insufficient forward planning and co-ordination between agencies.

These general concerns were certainly reflected across our sites. Whereas it was acknowledged that *Valuing People* had indeed made some impact upon the attention given to the service, the general view was that it remained a low priority and that funding was insufficient to effect any real change.

*When you look at the national service frameworks for older people and mental health, they have got new monies coming in, but that's not happening in learning disabilities. We are having to re-jig what we have got.*

(Social Services Learning Disability Manager)

*We have enough money to run what we have at the moment, but we have to modernise everything with the same money. It's very hard to do. When we were closing hospitals we had a bridging fund that allowed us to double-fund.*

(Policy Officer)

A more senior manager in social services was blunt about the implications of funding shortage:

*Now the Special Transitional Grant has run out, what it basically means for the learning disability budget is that growth can only come from older people dying. Effectively you have a kind of net swing from older people's community care into learning disability.*

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Such a manoeuvre implies that learning disability is a relatively high priority for any uncommitted monies, but this may not be the case among all partners and across all localities.

*You won't find learning disability high on anybody's agenda. But we have just been told at the eleventh hour that learning disability services have to feature in the Local Delivery Plan, so there has got to be a 3-year commentary.*

(NHS Senior Manager)

However, even the stratagems described above seemed to be doing little to hoist transition planning very high up the learning disability agenda. As already noted, some Learning Disability Partnership Boards seemed to be very lax in the appointment of Transition Champions, and transition was not especially high on the priorities of boards.

*It's not a high priority at the moment. The main issues are the housing and accommodation strategy that we have to have developed by February 2003, and the modernisation of day-services strategy that we have to have developed by 2003.*

(Board Member, Social Services)

*Transition doesn't actually have a target laid out in Valuing People. There are guidelines as to how we should be doing it, but it doesn't actually give us any targets. If you have got to report back on something then it makes you a bit more accountable.*

(Local-Authority Commissioning Manager)

*Everything is a priority except transitions. We have not got an authority statement on it. We need to have somebody at senior management level taking on the responsibility.*

(Transition Worker)

In these circumstances, the quest for cost savings was often directed towards pulling young people back from expensive out-of-area placements:

*We have got to look at ways of how funding is being spent, and we are looking at services we might want to decommission. The classic one is the out-of-area placement; it's a massive issue for us.*

(PCT Commissioning Manager)

The funding and potential decommissioning of such placements was a recurring tension across our sites, with different aspirations and expectations being held by commissioners, providers and recipients. One Policy Officer lamented the seeming collusion between parents and providers:

*Sometimes children find themselves away at special schools and parents have the idea that this funding will continue forever, but we are not into away special schools for adults. We want to make sure we have got local services for local people, so we go along and challenge them. I am trying to be tactful here, but some parents will have their expectations about the future raised by service providers, whilst the commissioners have a different point of view. There is a tension there, isn't there?*

(Local-Authority Policy Officer)

What all of this suggests is that in the absence of readily available funding the only way transition planning is likely to move up the learning disability agenda is by attaching centrally imposed requirements that are rigorously performance-managed. This goes against the trend towards a new localism



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and the attempt to decrease the number of performance-managed targets, but may be a necessary evil. The NSF for children and young people (Department of Health, 2004c) is something of a step in this direction, with a standard on transition into adulthood. It is stated that:

*Disabled young people need high quality, multi-agency support to allow them to have choice and control over life decisions, and to be aware of what opportunities are open to them, and the range of support they may need to access.*

In pursuit of this end, it is said that local authorities, PCTs and NHS Trusts should ensure that:

- transition planning has as its main focus the fulfilment of the hopes, dreams and potential of the disabled young person, in particular to maximise education, training and employment opportunities, to enjoy social relationships and to live independently;
- transition plans take a PCP approach which is consistent with the Special Educational Needs Code of Practice;
- a multi-agency transition group is in place that includes a Transition Champion from the Learning Disability Partnership Board, has representatives from Connexions, the local authority (including social care, education and housing), the LSC, health, user representation and voluntary organisations, and assumes responsibility for overseeing transitional arrangements at strategic and operational levels, and for agreeing inter-agency protocols;
- young disabled people aged 16 years and above are supported in the use of Direct Payments;
- specific arrangements are made for managing the transition of those with high levels of need, those in residential schools/living away from home, looked after young people leaving care and those with rare conditions;
- agencies develop local strategies to widen education, training and employment opportunities for disabled young people, and
- health services develop appropriate adolescent/young persons services with a view to enabling smooth transition to comprehensive adult multi-disciplinary care.

Whereas these standards will carry widespread support, they are noticeable for their lack of specificity. Given the evidence in this report on the persistence of an implementation gap in respect of even legally based requirements, there has to be some scepticism about the extent to which the NSF will radically alter transition policy and practice.

### **5.5.2 Short- versus long-term perspectives on transition planning**

One of the reasons we selected this transition in comparison with stroke was the anticipated element of predictability in terms of preparation and planning. All or most of the young people will have been known to at least some of the transition partners since childhood, and this might be expected to facilitate a long-term and considered approach to planning. This does not appear to have been the case. All respondents described a situation in which planning was at

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best relatively short term and at worst completely reactive. One adult services manager (social services) summed up a typical situation:

*We tend to really only plan with these kids when they are approaching 18, most of them will be staying on at school until 19. We will identify those we think are eligible for a service and offer them an assessment. We try to be proactive.*

The capacity to take a coherent long-term view was hindered by confusion and disagreement over responsibility for undertaking the task:

*The adult services manager got in touch with me saying 'people keep popping out of the woodwork at 18 and we don't know they are coming through'. We have got to alert people to the fact that they are coming through, you just can't rely on children's social services to do it.*

(Connexions Manager)

From the perspective of providers and families, the consequences of a short-term perspective could be difficult, especially where some budgetary brinksmanship between different agencies was involved:

*You usually have to wait until a week before they are going before you know if you have funding. They argue amongst themselves.*

(Parent)

*Providers need to be able to position themselves to provide us with the services we actually need. It should be straightforward to do because it's a low-volume service and the numbers are quite stable.*

(Area Manager)

Given the weak links between children's and adult services described above, this degree of proactive planning may well be the best that could be achieved in the circumstances, but it falls well short of what is required. Most of the key partners recognised this. Their reactions, however, ranged from anger to bemusement.

*Gary was 18 last March and has still yet to be seen by an adult social worker because they claimed they weren't told he was coming and weren't prepared for him. But he was born learning disabled, they have had 18 years to know he was coming. I sometimes wonder if they imagine our children won't survive to adulthood. They have been in the system since birth.*

(Parent)

*They have had 18 years warning to do something. It isn't bloody difficult. The impression is total and absolute chaos, knee-jerk management all the way through.*

(Parent)

*I get applications to fund specialist college placements in September for courses due to begin that month. Why is it happening? Why hasn't there been better planning? How can we plan for placements that are going to be needed? Only by having information at an early stage, and we aren't getting that.*

(LSC Manager)

*We need to get hold of the transition phase as soon as possible and not leave it until young people are transferring between our children's and adult services. We could do a lot of forecasting around need and cost if we picked it up earlier.*

(Social Services Senior Manager)

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*Somebody should be doing a needs analysis. There needs to be a consideration as to what our future needs are going to be, and what we should be providing for the future.*

(Senior NHS Manager)

Not everyone shared the view that transition planning needs a long run-in. For one children's services manager there was danger in making decisions too early in the process:

*I always thought the statement on transition started too early. We might be trying to railroad kids down some decisions they made 2 years ago when they have changed their mind three times in the interim period. But the earlier the better seemed to be the word from parents. I think they feel the options are a bit nebulous until they almost get to the death, and then there's a terrible rushing around.*

The problem is widely recognised, the means for dealing with it are understood, but no action is taken. This is an important point. The pervasive discontinuity does not arise from insuperable technical obstacles or failure to understand the nature of the problem. It arises from confusion and bargaining over inter-organisational relationships and responsibilities. As one *Valuing People* Support Officer noted:

*The carers must feel incredibly frustrated. It's only a maximum of about 30 people leaving each year. It's not exactly filling Old Trafford, is it?*

In our county locality the first signs of getting to grips with a strategic approach to transition planning were evident as described above with the formation of operational and strategic joint forums:

*What I did last week was report to the Integrated Commissioning Board with an estimated cost of how much we are going to need to be able to provide the services that we have identified for young people over the next 2 years. There were a few deep breaths and an 'oh well'! But looking at the big picture, it's the first time we have done that. We can now actually give them a figure on how much they are going to need to commit. It's never been done before.*

(Transitions Coordinator)

One of our other localities was arriving at the same position:

*We recognised that there wasn't actually a system for identifying the cohort of young people coming through who had statements of special education needs. Connexions is having the first stab at sitting down at the end of the spring term to actually go through the list of young people with statements and finding those coming forward for transition.*

(Strategic Manager, Children's Services)

Whereas it is positive to discover that such steps are being taken to address discontinuity, there may equally be some puzzlement that it has taken so long for such basic and self-evident measures to be introduced. The creation of the LSC was, in part, intended to address precisely this discontinuity, but their role as strategic planners in the world of continuing education had yet to be decisive in our localities.

Following the Learning and Skills Act 2000, the LSC is now responsible for policy, strategic planning and funding of post-16 learning (up to university level) and promoting equality of opportunity in such education. It has taken over these roles from the FEFC and the Training and Enterprise Councils. The LSC has a specific duty to have regard to the education and training needs of

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learners with disabilities, and is aided by the 47 local LSCs which have been established in England, each of which will have a contact person for learning disabilities and must consult local authorities on their local policies and priorities. Section 140 of the act sets out the statutory provision for the assessment of young people with learning difficulties who are undertaking or are likely to undertake post-16 education or training or higher education. Under Section 13 of the act, the LSC has a particular duty to have regard to the contents of these assessments and the needs of the young person assessed, when discharging its functions for those under 25 who have learning disabilities.

In undertaking these duties, LSCs will be expected to form a close relationship with local Connexions Services on whom they will rely for Section 140 assessment and planning paperwork. For Connexions PAs working in the learning disability field, this may be their key role. One PA found it both advantageous and disadvantageous:

*I suppose the strongest role we have as co-ordinators is funding applications to the LSC because everything always comes through us. We are seen as the hope there. What needs to happen is for us to be seen as the hope for the rest of the time really.*

Generally, relationships between the LSC and local Connexions Services seemed well established, with the LSCs anxious to gauge the impact upon their budgets of expensive cases coming through to post-16 education. However, relationships with other potential funding agencies – especially social services – were sometimes fraught. One LSC manager wondered whether there was a ‘social services culture’ that prevented a relationship with the LSC, but typically the disagreements were about money. LSC funding guidance states that young people must be progressing towards a qualification, and if a college states that someone has already reached their learning potential, then the LSC will withdraw funding. It is normally at this point that social services may be faced with a potentially large funding commitment that has not been anticipated. An LSC manager described one outcome of this situation:

*At the end of the day if social services turn round and say ‘we haven’t got any money left’, the LSC has in the past picked up the whole tab. I look like I have got egg on my face, and I have said to National Office I am not happy about this. I pursued social services, and the LEA tried to influence social services, but they just said ‘our budget’s spent’. National Office said we would pick up the tab – and now social services know that.*

This general failure to take a long-term perspective is borne out by the recent report from the Learning Disability Task Force (2004) that discovered huge weaknesses in the collation of accurate demographic and financial information surrounding the learning disability population. Much of the information was said to be in a format that defied analysis or comparison, or was not readily available. Overall, as Beresford (2004) has argued:

*A flexible long-term view is required with sufficient time given to planning, information gathering, experiencing possible options before transition, and then a recognition both of the need for ongoing support and the fact that transition is not achieved in a single step, but rather must be in tune with a young person’s individual abilities and needs.*

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### **5.5.3 Organisational complexity and environmental turbulence**

When separate organisations are going through their own organisational changes, partnership working tends to take a back seat. Nationally, many of the key transition partners were undergoing radical transformation at the time of our fieldwork. Social services were moving from a Seeböhm-style committee system to one based around Cabinet portfolios; PCTs had only relatively recently taken over from the barely established Primary Care Groups; the Connexions Service was just coming into existence; LSCs were still settling in after succeeding the Further Education Funding Council; councils were being invited to bid for Pathfinder Children's Trust status; and Learning Disability Partnership Boards were in the earliest stage of development. This is not a promising scenario for pursuing the complex multi-agency and multi-professional configurations needed for an effective transition service.

It would be wrong not to acknowledge the impact of this turbulence upon local partnership working. One of our sites offers an illustration. In addition to the factors identified above, there was also talk of moving services into an existing specialist trust for mental health and learning disability services that served contiguous localities. One respondent felt that the culmination of these changes had created a formidable barrier to shared working that had not yet been breached:

*There have been no talks at top level about what the future might look like in terms of learning disability services across health, social services and others. There is no over-arching strategic vision. This needs to be sorted out before we can move forward.*

(NHS Manager)

Nevertheless, in the same locality a great deal of multi-agency effort had been put into two ventures – a strategic partnership for children and young people, and a bid for Children's Trust status. In the case of the former, 19 different plans relating to children and young people were being brought together in a more coherent way by locating them in four segments – early years, children in need, child protection and child health. Each of these groups had chairs and sub-groups. The transition issue would be part of a sub-group focusing upon children with disabilities, but this was seen as one of the more problematic areas:

*Some of these areas have really strong links between organisations, but in the case of children with disabilities we haven't been able to develop a strong lead in any of the other agencies to take responsibility for carrying that forward.*

(Social Services Senior Manager)

At the time of the fieldwork a bid for Children's Trust status was being prepared in the locality – a bid that was subsequently successful. However, although this was seen as having huge potential for co-ordinating services for children, it was unclear that it would contribute to a more effective approach to transition:

*It would solve a lot of the issues we are currently working with – pooled budgets, care management for children with disabilities, who's responsible for what. But it could make the transition issue worse. That issue is still there.*

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(Senior Manager, Child Care, Social Services)

What seems to be happening here is that local partnership energy is devoted to new, high-profile areas, rather than addressing enduring difficulties. Moreover, the tendency is – understandably – to focus upon relatively discrete areas in which there seems to be a reasonable likelihood of success, rather than transition planning and activity. Indeed, transition seemed to have assumed the mantle of a ‘wicked issue’ – those policy matters that are particularly difficult to resolve because:

- the problem itself is hard to define;
- the causal chains are difficult (if not impossible) to unravel;
- complex inter-dependencies are involved.

This implies a complex web of organisations and individuals that need to work together, as compared with the features of old partnerships typified by the arrangements that developed for resettlement from long-stay hospitals. The features that underpinned these ‘old’ relationships bore many of the characteristics of what Challis *et al.* (1988) have described as ‘planned bargaining’:

- partnerships come together with the intention of delivering pre-set common objectives;
- there is confidence that the objectives are the right ones, based upon experience of what works;
- the focus is the resolution of existing problems rather than the anticipation of future ones;
- partnership working is relatively small scale and *ad hoc*, rather than part of a broader partnership design.

Wicked issues require ways of working that are different to those found in old partnerships. These include:

- understanding: recognising that understanding is partial and is best seen through a variety of perspectives;
- thinking: pursuing the holistic and looking for interactions and their relationships;
- working: tolerating not knowing, and accepting different perspectives, approaches and styles;
- involving: inclusive, drawing in as wide an array of organisations and interests as possible, and open to public involvement;
- learning: encouraging experimentation and diversity, and reflecting upon what has been learned.

It was not evident in our sites that the partnering relationships so far attained were sufficient to sustain such an approach – one rooted in networks rather than structures. There were some examples of co-location of kindred professional groupings, which has the potential to facilitate an informal approach based upon mutual trust and respect. In one locality there was a joint team for adults with learning disability, including social workers, community nurses and therapists, all managed by a team leader based in social services – but there was no comparable joint team for children. In this case, nurses were encouraged to undertake a care management role in much the same way as social workers, but were seen as reluctant to get involved

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with financial means-testing, and less accustomed to being accountable for their actions to a team manager.

Similarly, at a different site there was co-location of social workers, support workers and healthcare professionals, operating a system of joint referrals and assessments, but the system was not strongly formalised: 'different people doing different things but coming together to have meetings', as one respondent described it. In this case, there were still different line-management structures, different processes and different systems. As with relationships at the inter-organisational level, there were plans in hand to review these relationships at inter-professional level, thereby adding to the feeling of 'environmental turbulence'.

Many of these difficulties might expect to be replicated in county-wide structures with two-tier local government and a multiplicity of PCTs. In the county area in this study, for example, there are now eight PCTs, compared with four health authorities in the past, and in the case of learning disability there are eight Partnership Boards. This complexity has been addressed by devolving much responsibility to the eight localities, each with a separate Learning Disability Partnership Board:

*Now we only have to think about 200 000 people, not the 1.2 million across the county.*

However, devolution is not the same as autonomy, and the local partners still had a 'selling job' to undertake with their parent organisations:

*As soon as anything is agreed locally, the process of selling it to everyone else will have to take place. Health will have to make contact with the other PCTs and ask their view, the Connexions representative is going to have to contact her counterparts elsewhere, and even education and social services representatives will have to do a selling job within their own organisations. It's not a neat arrangement.*

(Children's Services Manager)

One of factors behind this is the need to ensure some degree of equity across the county:

*We need some kind of standardised approach in terms of making sure that there's some kind of consistency across the 12 districts and the eight PCTs. You can have local flexibility and some tailoring to local circumstances, but you have got to manage the issue of consistency. If you look at transitions, you can't have a really fantastic arrangement in a couple of districts and nothing in the others.*

(Local-Authority Manager)

Since our fieldwork was undertaken, the pace of change has accelerated, most noticeably with the reforms associated with the *Every Child Matters* Green Paper (Chief Secretary to the Treasury, 2003). The scale of the remit is probably best seen in the Children Act 2004 itself. The first nine clauses are concerned with the establishment of the Children's Commissioner, and there are some miscellaneous changes to such things as private fostering in Part 5, but the bulk of the act rests squarely upon systematic rather than *ad hoc* partnership working. This is shown in Table 2.

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**Table 2 Sections in the Children Act 2004 requiring partnership working**

Section	Description
Section 10: The Duty to Cooperate	A duty is placed on local authorities to make arrangements to promote co-operation between agencies in order to improve children's well-being defined by reference to the five outcomes, and a duty on key partners to take part in those arrangements. It also provides a new power to allow pooling of resources in support of these arrangements.
Section 11: The Duty to Safeguard and Promote Welfare	Creates a duty for the key agencies who work with children to put in place arrangements to make sure that they take account of the need to safeguard and promote the welfare of children when doing their jobs.
Section 12: Information Sharing	Allows further secondary legislation and statutory guidance to be made with respect to setting up databases or indexes that contain basic information about children and young people and their families.
Sections 13–16: Local Safeguarding Children's Boards	Requires that local authorities set up statutory local Learning and Skills Council Boards, and that the key partners take part.
Section 17: The Children & Young Person's Plan	Establishes a single plan to replace a range of current statutory planning.
Sections 18 and 19: Director of Children's Services and Lead Member	To be appointed by local authorities and to be responsible for, as a minimum, education and children's social services functions. Local authorities have discretion to add other relevant functions such as leisure or housing if they feel it is appropriate.
Sections 20–24: Integrated Inspection	Require an integrated-inspection framework to be established by the relevant inspectorates to inform future inspections of all services for children.

Where all of this leaves the transition from adolescence to young adulthood is far from clear. The danger is that by institutionalising the split between children's services and adult services, the gap between the two grows wider, and transition falls between the two stools. Some of our respondents foresaw just such a possibility:

*My big fear is that we get the children's organisation under Every Child Matters, and the barriers go up. Hopefully that won't happen. We will have to wait and see.*

(Transitions Coordinator)

*Suddenly it's children's services and adult services, and never the twain shall meet. Transition could become that much more problematic.*

(Children's Trust Coordinator)



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The appointment of a Director of Children's Services has become a legal requirement under Sections 18 and 19 of the Children Act 2004, with over half of all relevant authorities having already made an appointment. The responsibility of the Director of Children's Services includes making the necessary arrangements to secure co-operation, and to be a clear channel of accountability. However, the managerial remit of the Director of Children's Services runs only within the combined education and social care functions of the local authority, and it is unclear how other stakeholders vital to the specific transition focus of this study will be held accountable. A related concern is that the majority of appointments have come from the ranks of former directors of education whose understanding of the multi-faceted nature of transition will be limited.

It is perhaps for this reason that the recently produced guidance on the new role of Director of Adult Social Services makes specific mention of the importance of dealing with issues of transition (Department of Health, 2005). Several points are emphasised:

- The Director of Adult Social Services, working with the Director of Children's Services, should ensure that information about adult services is provided to young people approaching the age where they will make the transition from childhood to adult life, in order to facilitate their involvement in decisions about service provision.
- The Director of Adult Social Services should be responsible for the arrangements to support the transition of service users between different service providers, and between children's and adult services – again a task to be undertaken collaboratively with the Director of Children's Services. Specific mention in this respect is made of learning disability services.
- The Director of Adult Social Services should work closely with the Director of Children's Services to assess and meet the needs of children who are entering the transition phase from childhood to becoming adults, ensuring that adult services are sufficiently aware of the needs of children and their relationships to adults requiring services.

In one sense this is an enormously encouraging recognition of the possibility that transition issues are notably at risk of falling between two stools – of becoming 'nobody's baby'. However, our evidence would point to two continuing difficulties. First, the transition from adolescence to young adulthood already falls between several stools and has no real co-ordination or leadership. The guidance for Directors of Adult Social Services implies that such co-ordination currently exists but must not be lost as a result of organisational turbulence. Second, this sort of general injunction is precisely the sort of top-down approach that in the past has elicited little more than a cosmetic shift in outcomes.

In addition, at the time of writing, a Green Paper on the youth services is imminent and seems likely to create a further bout of environmental turbulence. The Connexions Service, although scarcely established, seems likely to lose its separate identity and be incorporated in the new Children's Trusts that will be established nationwide over the next year or two. Such a move may reinforce the fears expressed above that the divide between

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children's and adult services will become even more pronounced, with transition failing to be a priority for either side.

### **5.5.4 Transition to what?**

Ultimately an effective transition serves as a bridge – from adolescence to young adulthood. What lies at the end of this bridge is critical, for a good transition will count for nothing if there are no real choices about future destinations. Our study has focused upon intersections around transition working, but in doing so has inevitably taken in elements of post-transition choices. Heslop *et al.* (2001) come to a somewhat emphatic conclusion in their study:

*One of the most striking findings from this project was how little difference transition planning seemed to make to the young people's lives, particularly in relation to employment and housing opportunities. This was largely because there were so few options available. The lack of any real choice or options was a reason given by parents for why it was difficult for their children to participate in decision-making about their future; it was also, for many parents, the most negative thing about the planning process.*

(ibid, p.108)

If the transition from school to college at 18/19 is the visible transition, then the transition to a post-college destination a few years later is the invisible transition. It is not surrounded by laws and regulations specifying what should be done, by whom and at what point. At the heart of this is the reality that too often there are so few options available, and that whatever skills may have been acquired in the preceding years will not be put to optimum use. One short-term response to this has been to extend continuing education beyond the first 3 years:

*There's quite a few now coming up to 30 who are still in college. Paul has done 3 years full-time, and now he's going part-time for another year and another – however long it takes. It's good because once they leave college there is nothing for them, not a thing.*

(Parent)

*He's at college 5 days a week for another 3 years. What happens after that, I haven't got the faintest idea.*

(Parent)

*It's automatically been day centre for people with high support needs and college for people who don't have high support needs. And when you have done all sorts of courses there's still nothing been found for you as an alternative to the day centre, so you actually come knocking on our door at 25.*

(Day Centre officer)

One front-line worker put the whole transition planning issue into just such a perspective:

*My concern is that we will just focus upon transition as a process because that's what is meaningful to us, and it won't actually be seen in the broader context of what is meaningful to a person in the whole context of their life. So what, if we provide a wonderful transition process, if somebody is going to be chucked out the other end and made redundant for 40 years?*

The important distinction to be drawn here is that made by Beresford (2004) between transition between services, and the process of transition from child

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to adult status as indicated by conventional accomplishments such as achieving work and leaving home. Transition from child to adult services can take place at a time when it is thought that the individual's needs would be better met by adult services, or because for reasons of chronological age, the individual is no longer a 'child' and not eligible for a service. However, these sorts of transitions are not necessarily about supporting the process of transition to adulthood – transition services are time-limited, and may therefore not be available when a young person is actually seeking to accomplish some aspect of adult status. Responding to this problem involves a return to the ideas underpinning PCP – that the purpose of transition planning is not to move individuals from one service to another, but rather to support a young adult to move towards a new life stage.

### **5.5.5 Transition: everybody's distant relative?**

Transition planning is characterised by a plethora of strictures, yet there is still no clarity on who can or should take the lead, or co-ordinate the partnership. Despite the guidance, exhortation and law surrounding the issue of transition, it can still fit Sir Roy Griffiths' classic description of community care – everybody's distant relative but nobody's baby – and this can apply at both strategic and operational levels. One manager summed up the dilemma in his locality:

*When we started looking at it we realised we didn't have a transition process at all. There was very little link to employment services, zero link with day services and not a great deal of work between children's and adult services. And poor old Connexions just felt stuck in the middle.*

From a parental perspective, the problem could seem only too obvious:

*There are too many bodies and nobody takes ownership of anything. There is no clear leader; no one is taking charge. There needs to be someone with enough power and responsibility to take real ownership.*

This can mean that one party ends up unwillingly with the unwanted child:

*It has always been seen as social services trying to sort out the transitions issue, but without making any real progress, probably because it wasn't seen as a social services responsibility. Basically it's the adult team that picks up the mess, but I get frustrated at the lack of other people doing it.*

(Social Services Manager, Adult Services)

One special educational needs co-ordinator graphically described an ostensibly successful regional meeting on transition planning that he had convened:

*All the LSCs turned up, all the LEAs turned up, all the Connexions Partnerships turned up, lots of people there, it was going well, a real momentum. The bandwagon was rolling – and then I realised there wasn't a driver.*

Securing clarity on who does what in relation to transition was proving to be difficult in all localities. Under financial pressure, the common tendency was for organisations to focus upon their 'core business' – a strategy that assumes some other agency picks up 'non-core business'. The difficulty arises where an issue falls into nobody's core business, and transition seems to fall into this category. A children's social services manager explained the predicament from his perspective:

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*What we are looking to is a clearer view, and a clearer understanding by others, of what our core business is. We are the ones responsible in child protection cases, looked-after children and disabled children. This leads on to other agencies having to extend what they do, say in education and Connexions. There is a huge misunderstanding about what social services do, and other agencies are disgruntled. I am reluctant to use the word confrontation, but I suppose that's the word that comes to mind.*

In this respect, then, our findings echo those of Grove and Giraud-Saunders (2002):

*Work must be done to clarify expectations about what Education, Social Services, Connexions and Employment Services are each supposed to do. This needs to happen at national, area and local level.*

(p.29)

However, it is not just lack of partnership accountability that is important here. There is also a pronounced policy-implementation gap that needs to be unpicked. This is a point made forcefully by Heslop *et al.* (2001):

*A lot of the changes wanted by parents were exactly what statutory guidance says should routinely happen ... Clearly for many of the families in our survey, statutory guidance was not being followed as it should have been.'*

(p.91)

The central issue here is the 'policy-action relationship' (Barrett and Fudge, 1981; Hill and Hupe, 2002) – a process of interaction and negotiation between those seeking to put policy into effect, and those upon whom action depends. The ways in which this tension is worked through in the implementation process is what will shape the effectiveness of transition processes. The rational, top-down approach that has hitherto been taken by central government displays insufficient appreciation of the importance of bottom-up implementation factors.

### **5.5.6 Responding through partnership**

Even over the relatively short period of our investigation, it would be fair to say that the transition issue was beginning to rise up local agendas. The growing body of research exposing the inadequacy of the transition from adolescence to young adulthood had resulted in ever louder noises from central government on the need for localities to improve their performance, whether through existing arrangements (such as the Special Educational Needs Code of Practice or Connexions and *Valuing People* guidance) or through new requirements like the NSF for children. In addition there is the possibility that this research project itself might have focused some minds more sharply. Although we conclude that a top-down implementation model is not itself sufficient to bring about genuine change, it is nevertheless the case that central government can create a collaborative climate in which a joint approach is more likely to flourish.

In each of our localities, the green shoots of partnership were beginning to emerge. In our county authority a significant amount of structural and process change was being put into place, which – if effective – would pave the way for a stronger partnership approach. This model consists of three levels of partnership activity.

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### **Operational groups**

The original aim at this level was to establish a group of operational staff who will be responsible for planning individual or group services for young people who are facing the transition from children's to adult services. As this suggests, the groups were intended as planning forums for individual cases but there have been questions about how far these groups are appropriate for that purpose: (a) given that the legal responsibility is for the social services department adult team actually to make an assessment and commission services within their own financial constraints, etc; and (b) the groups consist of professionals only and not the young people and families themselves. The operational groups have, therefore, evolved more into information exchanges only – they are the place where different agencies/professionals make each other aware of young people who they need to work with and monitor progress. Overall, the groups are felt to have been very positive for building trust between professionals from the different agencies (e.g. to share names of young people on their different lists) and to bring together different perspectives in approaching provision for different individuals.

*The group will look at those people coming into the 16–18 age bracket and their needs would be followed through on a person-centred basis so we would know each of the young people coming through. We won't be in the situation where somebody would knock on the door of other services saying 'I have got a young person here who is coming back from an away school and is costing us £100 000, and you have got to take over.*

(Fieldwork Manager, Children's Social Care)

*You do feel everybody is there for the same purpose, to make sure transition is a lot smoother than it was, rather than all these disparate people doing their own bit and never coming together.*

(Connexions PA)

### **Development and Advisory Group**

The overall aim at this level is to establish a partnership structure which will work together to ensure there is a cohesive and seamless system in place for young adults with a learning disability who are facing the transition from children's to adult services. The group meets approximately monthly or bi-monthly to discuss necessary service developments and is chaired by the Integrated Commissioning Manager. The rest of the membership has been higher-/middle-level service managers from relevant agencies. In October 2003 this group merged with the Transitions Task Group of the Learning Disability Partnership Board (see below). In effect, at this level the work of the operational group is translated into a strategic perspective over a longer time span:

*The group looks at patterns that are coming through so that we know that there are so many children coming through with Asperger's syndrome, for example, and that we need to think about what we are going to do with these children 3 years before they leave school.*

(Fieldwork Manager, Children's Services)

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### ***Partnership Board and Integrated Commissioning Board***

The Learning Disability Partnership Board relates to a conterminous Integrated Commissioning Board that manages the pooled budget for adult learning disability services. There are eight pooled budgets agreed under Section 31 of the Health Act 1999 and hosted by the county council, each relating to separate PCT areas. The Partnership Board brings together the health and social services partners, together with representatives from education, employment, the local borough councils and Connexions. Members of the local Integrated Commissioning Board also sit on the Partnership Board.

The Partnership Board has three networks attached: the service users/self-advocates network; the family/carers network; and the service providers network. It also has 11 task groups, of which the following have been the ones relevant to transitions:

- Transitions Task Group (which has user/carer membership, and deals with tasks such as producing a transitions information leaflet),
- Person Centred Planning Task Group,
- Health Task Group (which is looking at Health Action Plans).

Following discussions over summer 2003, it was agreed that the Transitions Task Group and the Development and Advisory Group will merge because their remits overlap. Finally, a separate (time-limited) county-wide group was led by the county-level Social Services Fieldwork Manager for Children with Disabilities and involves social services, education, a representative from Connexions and one PCT representing the eight PCTs. Its remit was to produce new protocols and procedures, and an information pack, for dealing with transitions in general; that is, identifying children at 14-plus and providing a pathway through the different agencies for all children with disabilities, not just those with learning disabilities.

Elsewhere, there were continuing moves towards both integrated front-line teams and more coherent strategic arrangements – a multi-agency steering group in one of the other localities, along with a single management structure for the learning disability community nursing service and social work team for children with disabilities. Elsewhere there has been a transitions protocol signed up to by the main partners, along with the appointment of an additional transitions worker, and in another locality the use of the Connexions Section 140 document as the basis for a multi-disciplinary assessment. It has not been part of our brief to assess the impact of these new approaches, and it would be churlish not to welcome them as potential improvements. However, our analysis has identified such deep and complex discontinuities at every level, that it would be unrealistic to expect instant or even early success.

## ***5.6 Summary and conclusions***

This report explicitly looks at issues of a general nature across the sites – it is not a detailed description and analysis of activity in any one locality. The aim was to identify recurring factors that affect continuity or discontinuity of care in respect of the transition from adolescence to young adulthood for people with a learning disability.

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### **5.6.1 Analytical framework**

In addition to the general concepts of inter-organisational and inter-professional complexity used to shape our stroke case study for this section of the report the analytical framework we use is an adapted version of that arising from the multi-method review undertaken by While *et al.* (2004) for the SDO Programme. We have found the most relevant categories to be as follows:

- inter-agency continuity: relationships between multiple services both horizontally (within each age band structure) and vertically (between services concerned with children and adults respectively);
- inter-professional continuity: relationships between multiple professionals both horizontally and vertically;
- personal professional continuity: the availability of one or more named individual professionals with whom the service user can establish and maintain a relationship.

As noted at the start of this section, the issues of the identity of the co-ordinating body and of the flexibility of services are also important, and woven into the analysis.

### **5.6.2 Horizontal inter-agency continuity**

The formal situation in relation to transition planning is explicit about the steps to be taken, the parties to be involved, and the scope of the exercise, but policy implementation is rarely straightforward, and the Special Educational Needs Code of Practice in relation to transition planning appears to be no exception. Much of this is at the level of inter-professional relationships, but this can be difficult to disentangle from inter-agency relationships. A particular issue emerged around discontinuity of information, where communications between some of the key partners in transition planning sometimes caused problems. Several types of communication difficulty can be identified: communication mismatching, communication delays, communication closure, communication gaps and communication confusion.

### **5.6.3 Vertical inter-agency continuity**

For most children the service world prior to the onset of young adulthood is dominated by the education system. However, whereas for most young people the dependence upon services diminishes, for those with a learning disability there tends to be a transfer from one set of services (for children) to another (for adults). As with transition planning per se, this transfer is not without legislation, guidance and exhortation – a range of legislation sets out the duties of social services professionals to provide support during the transition period. The wider evidence on the extent to which this is fulfilled is not promising. Our work reveals five discontinuities in the relationship between children's and adult social services: informational, financial, organisational, social and chronological. We also identify what we term the comfortable continuity from school to college, with transition to college seen as the only real choice. This also contributed to a narrow perception of

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transition that avoided consideration of the wider range of issues related to an appropriate adult life.

### **5.6.4 Horizontal inter-professional continuity**

Much of the difficulty here related to the looseness of professional relationships during the transition-planning process, and in particular the limited range of involvement at what are ostensibly crucial milestones in the young person's progression. It is clear from the Code of Practice that a wide range of professionals is expected to be involved in transition reviews – in principle the range of attendees might be expected to match the complexity of the issues to be addressed. Given the multi-faceted nature of transition, this principle might be expected to trigger widespread attendance. In reality, a recurring difficulty across our sites was the paucity of attendance at transition planning reviews, with comparisons often drawn between who ideally should attend, and who actually turns up. Several explanations were given: workload pressures, individual professional discretion, inappropriate scheduling and inter-authority wrangling.

### **5.6.5 Vertical inter-professional continuity**

A further issue that was very significant for carers was that of changing access to healthcare professionals. It has often been difficult for people with learning disabilities to maintain and improve their health. The key issue facing young people and their parents was the reduced nature and range of health support available after the transition from 'childhood'. Regular and ongoing appointments with known health professionals ceased, to be replaced by an injunction to contact services as and when help was needed. Even this more uncertain system can only function where comparable adult services are available, and this was often not the case, with shortages of occupational therapists, speech therapists, clinical psychologists and psychiatrists. Where young people have a dual diagnosis of learning disability and mental health needs, or complex health needs, local partnership arrangements may be inadequate to the task.

### **5.6.6 Lead agencies**

Transition involves such a wide range of stakeholders that two of the alternatives to partnership working – structural integration and lead agency status – were difficult to adopt. Hence the emphasis tended to be upon partnership working, and it was not always easy to see clear patterns of responsibility and accountability for ensuring an effective transition was delivered. Several potential vehicles are identifiable: JIPs, Health Act flexibilities, Learning Disability Partnership Boards and Connexions Partnerships. None of these seemed to be dealing effectively with the transition process at the time of the research. However, one of our localities did have a model that – if effective – could pave the way for a stronger partnership approach.



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### **5.6.7 Personal professional continuity**

Two potential sources of personal professional continuity seem to be available, both of them relatively new phenomena – the new breed of Connexions PAs and dedicated Transition Workers, normally appointed within adult social care. The role of both is unclear, as is the relationship between them. PAs had high caseloads, and had yet to resolve issues around generic or specialist roles, and the training necessary to undertake the latter role effectively. The main response within social care to operational transition difficulties was to appoint dedicated staff (usually just one individual) to act as a transitions co-ordinator. This sort of post may be caseload-based, or may involve more of a co-ordination role, facilitating the work of other professions and services. Only in one of the three localities did the role of Transition Co-ordinator seem to have a clear link into a broader strategic process. Here, the co-ordinator had been in post for 2 years and was jointly funded by health and social services. Although he had a small caseload, the thrust of his work was to develop a transitions database for the Integrated Commissioning Board so that proper future planning could take place. With a clear link into the Partnership Board, this role was markedly different to elsewhere, where the defining feature seemed to be responsibility without power. Relationships between the PAs and the Transition Workers varied. The key variable seemed to be the strength of the inter-personal relationship between the individuals concerned.

### **5.6.8 Flexibility**

In principle the dual contributions of sensitive transition planning during school years and the development of PCP thereafter offers the possibility of a flexible approach to support that adjusts to the needs of the individual over time. Difficulties with the formal transition planning process have already been noted. PCP still seemed to be at a very formative stage, and while it has the potential to be a useful way of putting young people at the heart of the transition planning process, but it had yet to be used for such a purpose in any of our sites. Direct Payments rarely featured as an alternative vehicle for securing flexible continuity.

The notion of flexibility is also at odds with some of the rigidity around what might be termed chronological discontinuity. The relationship between service provision and chronological age is important but unclear, and often resulted in the abrupt and sometimes seemingly arbitrary withdrawal of support. However, the most common obstacle to flexible continuity was simply the lack of adult options – a paucity of choice that raises the question, transition to what? Even if it were the case that the transition process itself is sensitively and appropriately handled – and this does not seem to be the case – the effort would have little point if the post-transition options were unacceptable. The way the system copes with this reality is to focus upon what is for most young people a relatively untroubled transition from school to college, and neglecting the much more problematic transition into adult life once college has ended. Gainful employment and independent living rarely surfaced as issues with any stakeholders in our fieldwork and the reality of life after college was often some form of day care.

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### **5.6.9 Concluding themes**

The overwhelming conclusion of this report is that the transition from adolescence to young adulthood for people with a learning disability is characterised by discontinuity rather than continuity. Within this broad judgement, several issues can be identified.

#### ***Competing priorities in learning disability***

It has not been easy to get a sense of urgency about the priority given to the transition issue in our localities. All have established some form of sub-group, but membership tends to come from front-line practitioners, with the group chaired by an operational manager or middle manager. Whereas this has the advantage of bringing together people who have a sharp understanding of the way transition works in practice, it tends to be insufficiently powerful to initiate and sustain real change across the transition system. Similarly, the appointment of Transition Co-ordinators has, in general, placed too much responsibility for systems change upon relatively junior staff. The priority given to learning disability in general, as well as the transition issue in particular, varied, but in general it was relatively low. In agencies other than social care, learning disability is a relatively low priority, and even in social services, there are other more pressing priorities. On the Learning Disability Partnership Boards, transition had yet to reach the top of an agenda dominated by financial constraints, the introduction of PCP, the re-shaping of day services and, in some cases, the closure of long-stay institutions. In the absence of readily available funding the only way transition planning is likely to move up the learning disability agenda is by attaching centrally imposed requirements that are rigorously performance managed. This goes against the trend towards a new localism and the attempt to decrease the number of performance-managed targets. However, the emerging NSF for children does seem likely to include a section on transition planning, and this may have a more galvanising effect than has been the case with *Valuing People*.

#### ***Short- versus long-term perspectives on transition planning***

One of the reasons we selected this transition as a comparison with stroke is the element of predictability in terms of preparation and planning. All or most of the young people will have been known to at least some of the transition partners since childhood, and this might be expected to facilitate a long-term and considered approach to planning. This does not appear to have been the case. All respondents described a situation in which planning was at best relatively short term and at worst completely reactive. The problem is widely recognised, the means for dealing with it are understood, but no action is taken. This is an important point. The pervasive discontinuity does not arise from insuperable technical obstacles or failure to understand the nature of the problem. It arises from confusion and bargaining over inter-organisational relationships and responsibilities.

#### ***Organisational complexity and environmental turbulence***

When separate organisations are going through their own organisational changes, partnership working tends to take a back seat. Nationally, many of the key transition partners are undergoing radical transformation. Social

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services are moving from a Seeböhm-style committee system to one based around Cabinet portfolios; PCTs are taking over from the barely established Primary Care Groups; the Connexions Service is just coming into existence; LSCs are still settling in after succeeding the Further Education Funding Council; and Learning Disability Partnership Boards are in the earliest stage of development. This is not a promising scenario for pursuing the complex multi-agency and multi-professional configurations needed for an effective transition service. It would be wrong not to acknowledge the impact of this turbulence upon local partnership working.

Nevertheless, in the same locality a great deal of multi-agency effort had been put into two ventures – a strategic partnership for children and young people, and a bid for Children's Trust status. In the case of the former, 19 different plans relating to children and young people were being brought together in a more coherent way by locating them in four segments – early years, children in need, child protection and child health. Each of these groups has chairs and sub-groups. The transition issue would be part of a sub-group focusing upon children with disabilities, but this was seen as one of the more problematic areas. What seems to be happening here is that local partnership energy is devoted to new, high-profile areas, rather than addressing enduring difficulties. Moreover, the tendency is – understandably – to focus upon relatively discrete areas in which there seems to be a reasonable likelihood of success, rather than transition planning and activity. Indeed, transition seemed to have assumed the mantle of a wicked issue – those policy matters that are particularly difficult to resolve because:

- the problem itself is hard to define;
- the causal chains are difficult (if not impossible) to unravel;
- complex inter-dependencies are involved.

### ***Transition to what?***

Ultimately an effective transition serves as a bridge – from adolescence to young adulthood. What lies at the end of this bridge is critical, for a good transition will count for nothing if there are no real choices about future destinations. If the transition from school to college at 18/19 is the visible transition, then the transition to a post-college destination a few years later is the invisible transition. It is not surrounded by laws and regulations specifying what should be done, by whom and at what point. At the heart of this is the reality that too often there are so few options available, and that whatever skills may have been acquired in the preceding years will not be put to optimum use. One short-term response to this has been to extend continuing education beyond the first 3 years.

### ***Transition: everybody's distant relative?***

Transition planning is characterised by a plethora of strictures, yet there is no clarity on who can or should take the lead, or co-ordinate the partnership. Despite the guidance, exhortation and law surrounding the issue of transition, it can still fit Sir Roy Griffiths' classic description of community care – everybody's distant relative but nobody's baby. Securing clarity on who does what in relation to transition was proving to be difficult in all localities. Under financial pressure, the common tendency was for organisations to focus upon

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their 'core business' – a strategy that assumes some other agency picks up 'non-core business'. The difficulty arises where an issue falls into nobody's core business, and transition seems to fall into this category. However, it is not just lack of partnership accountability that is important here. There is also a pronounced policy-implementation gap that needs to be unpicked.

### **Who pays the price?**

It seems appropriate to end this learning disabilities section of our report by returning to those who pay the price of ineffective transitions policy and practice – young people and their families. Our findings are in line with every other research investigation into the transition from adolescence to young adulthood for people with a learning disability – that it is a domain characterised more by discontinuity than continuity. This has an effect upon the lives of the people caught up in the process. Recently, Beresford (2004) concluded of her own and other research that:

*What is very clear from the research is that for young disabled people, the process of transition from children's services to adult services, and from childhood to adulthood, is complex, extremely problematic and, in many cases, highly unsatisfactory.*

(p.2)

In similar vein, Smart (2004) has recently concluded that:

*In support of previous research, this survey has found transition planning to be a long and stressful process for those involved. In the role of advocate for their child, parents often find themselves immersed in issues they have little understanding of or control over.*

(p.135)

Although this report has focused upon the role of public agencies in addressing the transition issue, it is in the privacy of family households and relationships that the price is paid. Of the young people and parents we interviewed, frustration and confusion were common themes, but sometimes this spilled over into desperation. One father whose daughter was very severely disabled and being educated in a residential setting told us:

*I went to the education review and said we must think about what we are going to do; she can't keep coming home. I discussed it with a law firm in Manchester and they said the only way it would happen was if we refused her entry to the house. For 5 years we have been pushing for a plan to get her settled into adult accommodation when she moved from school, somewhere she could grow up and be looked after. I wish we'd never bothered, we just gave ourselves a lot of grief. We ended up in a showdown with the social services manager who threatened to call the police and have me and my wife done for child abandonment.*

Where families find themselves unable to understand or influence transition arrangements, they can resort to other means that both reflect and add to their stressful situation, such as manipulation or aggression.

*A friend said to me 'have you been to the doctor?' and I said no. She said you have to go to the doctors and tell them he's [their son] making you depressed. I thought why should I play silly mind games like that just because I want what he should be getting anyway? Mind I did go to the doctor last year, I was depressed, but that was real. It's sad when you have to do things like that.*

(Mother)

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*The impression every parent gets is that if you keep your mouth shut the situation will stay the same. The only time you get anything is when you open your mouth, start complaining, fighting, being rude and obnoxious. I have done my bit of being rude and obnoxious to people unfortunately.*

(Father)

Most cases in our sample did not end up like this. Rather, the transition from school to college went relatively smoothly, albeit with little thought having been given to the transition to adult life – it was a transition between services but not between life stages. This real transition between life stages was safely postponed to 3 years or more ahead, with little real idea as to how it would be supported and addressed. However, it is important not to portray transition as a simple dichotomy between young people and their parents on the one hand, and service agencies on the other. The reality is that all of the parties wished to see change and improvement, but all found themselves locked into a vicious circle of frustration – discontinuity is primarily a feature of systems rather than individuals.

## Section 6 Comparative analysis and conclusions

### **6.1 Introduction**

The final step in this study is to synthesise the findings and provide some stepping stones on the route to a better understanding of continuity of care. In Section 3 we noted the emphasis that the current Government places on joined-up working. One fashionable way of trying to encapsulate the normative ideal situation is in terms of so-called whole-systems understanding and action. Official exhortation tends to focus upon a 'helicopter' perspective in which benign and inter-dependent partners realise the virtues of a highly co-ordinated approach to the design of services. In the case of older people, for example, a study by the Audit Commission (2002) suggests that a successful whole system requires three key elements:

- a shared vision rooted in the views of older people;
- a comprehensive range of services delivered by flexible, multi-professional teams;
- a way of guiding older people through the system to make sure they receive what they need, when they need it.

In similar vein, the Change Agent Team (Department of Health, 2003c) argues that:

*The Whole System is not simply a collection of organisations which need to work together, but a mix of different people, professions, services and buildings which have patients and users as their unifying concern, and deliver a range of services in a variety of settings to provide the right care, in the right place at the right time.*

We propose a rather different approach, beginning at the other end of the relationship – the worm's eye view rather the bird's eye view. In our case this is an approach that starts with the young people with a learning disability, and the older people who have had a severe stroke. Conceptually, it is an approach that has been perhaps best expressed by the American scholar, Richard Elmore, in his notion of backward mapping (Elmore, 1980, 1983, 1985). Elmore builds upon the critique of top-down implementation approaches by arguing that instead of regarding human beings as chains in a line of command, policy-makers should realise that policy is best implemented by what he terms backward mapping of problems and policy. He suggests we should begin:

*...with a concrete statement of the behaviour that creates the occasion for a policy intervention, describe a set of organisational operations that can be expected to affect that behaviour, describe the expected effect of these operations, and then describe for each level of the implementation process what effect one would expect that level to have on the target behaviour and what resources are required for that effect to occur.*

(Elmore, 1985, p.28)

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The imperative here, then, is to begin at the phase when the policy reaches its end point, then analyse and organise policy from the patterns of behaviour and conflict that exist – a process that will involve negotiation and consensus building. In defining backward mapping, Elmore focuses on individual actions as a starting point for analysis, depicting them as responses to problems or issues in the form of choices between alternatives. This constitutes recognition that in many policy areas – and most certainly in the two that have been the concern of this study – implementation actors are forced to make choices between programmes that conflict or interact with each other. He accordingly sees the concept as:

*...backward reasoning from the individual and organisational choices that are the hub of the problem to which policy is addressed, to the rules, procedures and structures that have the closest proximity to those choices, to the policy instruments available to affect those things, and hence to feasible policy objectives.*

(Elmore, 1981, p.1)

Elmore is one of the key proponents of the bottom-up approach to understanding the policy-implementation process. The goal of backward mapping is to isolate the critical points (or, as we have termed them in this report, hinge points) in a complex multi-agent relationship that have the closest proximity to the problem, and identify what needs to happen at those points to solve the problem.

Our prime focus throughout the study has been the perspective of the patient/service user and his or her carers. Following Elmore, we begin with the end point, the individuals who have had a severe stroke or the people with a learning disability who are making the transition from adolescence to young adulthood. We then examine the hinge points, viewed as inter-professional and inter-organisational issues, as problems of central-local relationships and as issues to be addressed within a joined-up-government approach. For care to be continuous there would need to be sensitivity to the critical hinge points within each of these spheres as well as an understanding of the linkages between them – in other words, both vertical and horizontal continuity.

### **6.2 Continuity of care: the individual's experience**

The past two decades have been characterised by a concern to involve and listen to service users. This has reflected an important acknowledgement by national-level policy-makers that the history of health and welfare provision has hitherto taken limited account of the views of those for whom the services are provided. What is less clear is the extent to which this engagement has been genuine, and whether it has made a difference to the extent and nature of support – and specifically in this case to user and carer perceptions of a continuous set of services. In the case of medicine the professionalisation of process and service delivery has remained powerful, with patient involvement tending to be limited to post-intervention 'satisfaction' surveys (Harrison and Pollitt, 1994; Harrison, 2004). In social care, however, the shift has been more pronounced (Joseph Rowntree Foundation, 2005) and has now become the driving force behind new Government proposals. The recent Green Paper on adult social care (Department of Health, 2005), for example, places the

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emphasis upon user-defined outcomes and personalisation of support, with Direct Payments to be more widely available in an attempt to tip the balance of power towards users rather than professionals.

In both services it is possible to argue that a degree of consensus existed on what a good service should look like. In the case of young people with a learning disability this was expressed in regulation and guidance on how transition proceedings should be conducted, and in the principles underpinning the *Valuing People* White Paper. In the case of stroke services a broad professional consensus is expressed in the range of guidance from government (the NSF for Older People, Standard 5), from professional bodies (Intercollegiate Working Party For Stroke, Royal College of Physicians); to some extent this is echoed in user and carer organisations' guidance (e.g. the Stroke Association's good-practice guidance). Equally, it is striking that these and other accounts tend to reflect the helicopter perspective mentioned above. That is, far from setting out genuinely person-centred accounts of services, and hence of continuity of care as perceived by service users, documents reflect an essentially managerial ideal.

Our work leads us to make three observations. First, the dominant tool of policy in relation to service delivery is the care pathway. Published guidance tends to represent care pathways as linear sequences of events. Whereas there were certainly elements of services common to all or most people in each of the case conditions in the study, it was also clear that there was considerable diversity between individuals' experiences. That is, individual service users do not all follow the same linear sequence of events. Indeed, it is difficult to see why linearity should be an ideal, given the stress placed on responding to individual needs, in order to provide genuinely person-centred care, in all areas of health and social care. This is, perhaps, why some commentators now talk about patient journeys, or patient trajectories, as these terms help to focus attention on the routes actually taken by service users.

Second, patients and service users are the only unifying element in continuity of care. We would argue that it is only the patient's/carer's experience of continuity that really matters. Our position moves on from the arguments advanced in the helpful review by Haggerty *et al.* (2003) for the SDO Programme, namely that it should be possible to synthesise the differing perspectives of service users, providers and managers, to arrive at a synthesis, or rounded appreciation of continuity of care. It also differs from an approach which assumes that there are such things as care pathways, which represent linear sequences of events that are both efficient and person-centred (Pinder *et al.*, 2005). Care-pathway representations imply that it is possible to reconcile individual and organisational objectives. We have seen that this view is not supported by our evidence, and that there are good reasons to doubt whether the linear production-line model is desirable, given that it is likely to conflict with any drive towards genuinely person-centred care. This might seem an obvious, even trite, statement but if so it is one that has escaped policy-makers and most commentators on care pathways. This study has focused, from the start, on individual service users as the generators of our cases, so it important not to fall into the trap of self-fulfilment – the study design assumed that service users were central to the story, and so it proved. Our argument is that no other party experiences the



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whole journey. Readers can assure themselves of this point by imagining drawing a diagram of a patient/user journey from the perspective of an individual. Even in a diagram of an idealised service, there will be limited or even no relationship between many of the people who provide treatment and care. The pathologist who performs tests in hospital for someone who has had a stroke does not need to communicate with the community nurse visiting that person later on, for example. Their contributions only make sense because they are focused on individual patients/users.

The third observation is that the nature of service integration in health and social care services remains poorly understood. While the pathologist is unlikely to communicate with the community nurse, many other providers do need to co-ordinate their activities. We found ample evidence that continuity depends as much on co-ordination of services occurring in parallel as in series – though official representations emphasise series or linear events far more than events in parallel. Continuity, intuitively, depends on efficient co-ordination across professional and organisational boundaries. Our study suggests that it is fruitful to focus on the co-ordination mechanisms at hinge points, to appreciate both what is and is not working, and we report on some of these below.

### **6.2.1 System characteristics**

These points about the conceptualisation of pathways, or journeys, influence the way we think about continuity of care. For example, it would be easy to interpret national guidance as meaning that all service users should leave hospital in the same way. But our study shows that, for people who had a stroke, the experience of leaving hospital differed in important respects from person to person, as well as from site to site. It is one thing to believe that the ideal is a standardised transfer process, and another to believe that variation is appropriate. The same can be said for people with a learning disability, where we again observed wide variations in the patterns of services accessed, over and beyond any differences between the three study sites. Whereas the two tracer conditions were very different from one another in important respects, it is possible to identify three common themes – communications, co-production and resources. These are usefully conceived as the three main structural features of continuity, revealed at the hinge points we studied.

Good, timely information provision to patients and carers is very important. Good information and good communication were sought and valued at all stages of the patient's journey – initially in terms of diagnosis, prognosis and immediate treatment; subsequently in terms of the goals, content and timetable for rehabilitation; certainly prior to and around the point of discharge from hospital; and, after patients left hospital. The provision of written and video information was generally thought to be very good, which provides a marked contrast to many users and carers in our learning disability case study. It was also evident that patient and carer groups facilitated by staff (as in South Tyneside) offered a valuable opportunity to obtain and share information with 'the real experts'.

A second feature is genuine involvement in goal-setting, care (and discharge) planning, and arranging post-discharge support. For stroke services, again,

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there was widespread satisfaction about the ways in which patients and carers were involved. In particular, carers valued the encouragement and opportunities typically given to come into hospital and learn about moving, handling and general support. The third issue is resources, broadly defined. Certain aspects of general hospital care were said by some patients to represent discontinuities of care. One was the shortage of therapy – whether in general or specifically out of hours; that is, at weekends. The latter was seen as anomalous in comparison with the ever-present medical and nursing staff. A second aspect of general care was the too-frequent use of the phrase ‘in a minute’ by nursing staff in response to patients’ requests for assistance. This was seen by almost all those who referred to it as a problem as a response stemming from undue pressures upon nurses.

### **6.2.2 The hinge points**

In general, in both of our case-study domains, patients, users and carers did not feel that services were operating as they should. Dissatisfaction tended to be more pronounced in the case of learning disability than with stroke services, where parents in particular generally took a dim – and often damning – view of both the process of support and the outcomes of intervention.

In the case of stroke services we found patients and their carers generally satisfied with most aspects of their treatment, rehabilitation and care. In many cases they were not merely satisfied but were full of praise. There were, however, some perceived shortcomings. Within hospital there were some reports – although, it is important to stress, from a minority of the 18 recruited patients – of problems with transfers between wards. In some cases such transfers represented a marked discontinuity of care. For example, in a small number of cases moves were required for bed-management purposes. In all cases transfers need to be handled carefully precisely because of the inevitable discontinuities as patients change staff, physical environment and ward routine. It is equally clear, of course, that many transfers are welcomed because the discontinuity represents a positive shift, for example from a general medical ward to a Stroke Rehabilitation Unit.

It was widely argued that hospital discharge is a significant hinge point in any patient journey. We found that most patients were satisfied with the processes of support. But it is evident that the ideal is rarely achieved, with service providers typically pointing to stretched resources as the limiting factor. The word discharge itself carries connotations of disruption or even breakage in care rather than of apparently seamless handover. Hence the widespread preference for the word transfer. Change of language alone, however, will not dispel the anxiety of patients leaving the 24-hour safety net of hospital after several weeks or months. Ahead lies apparent uncertainty about further progress with recovery and rehabilitation or about types and levels of care support. Ideally, therefore, patients need to see (literally) and talk to the staff who will be supporting them after they leave hospital. The ideal, it was argued, would be for these future carers to come into hospital at least once for a joint session with hospital staff and for the latter to attend jointly with community-based staff when patients are first at home. We saw no examples of this ideal in practice but some examples of hospital staff going out with patients and handing them over to family and carers. However

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apparently mundane, this represents joined-up working across agency and professional boundaries which is the essence of continuity of care. What is equally important, of course, is that this conscious effort to join up is matched in the care and support after discharge.

In contrast with this picture of widespread – though not unconditional – satisfaction with the experience of transition around the point of hospital discharge, the experiences of those users and carers in our learning disability case study seemed at best somewhat melancholy. Here the picture instead was one of poor information, limited involvement, and non-existent handover from children's services to adult services. Indeed, as we underlined in Section 5, users' and carers' experiences bear out our general conclusion that the transition from childhood to adulthood for people with a learning disability is characterised by discontinuity rather than continuity.

One of the starkest facets of this discontinuity is the scale of the change between children's and adult services. Thus from being able, within limits, to take for granted the receipt of paediatric physiotherapy, occupational therapy, speech and language therapy and educational psychology support, users step into adulthood to find many of these adult services either severely curtailed or unavailable. This was made even worse by the differences in the age relationship of particular services in individual localities, some stopping at 14 years of age, some at 16 and some on leaving school. As we say in our case-study report, 'the abrupt service deficit arising from chronologically based eligibility criteria was a constant cause of distress to families'. For many carers this sense of distress was compounded by the shock of having to pay for adult services which had been free for children, respite care being one important example. Conversely, there was for some the apparently perverse incentive of another 3 years' funding for college placements (i.e. from 19 to 22) if children stayed on in school until they were 19.

There was a widespread feeling that there is a lack of choice about post-school options – hence the desire of some families to postpone school leaving. Lack of choice here meant not just a lack of options (for example, college courses offered) but the lack of opportunity to make an informed choice. An even bigger concern for many, however, was the lack of choice after any period of further education. There was a clear impression that there is too much concentration on the relatively untroubled visible transition from school to college and too little on the invisible transition post-college to employment and independent living.

In some respects this mirrors the concern about longer-term care expressed by some people with strokes and their families. This is a concern that however important the prior stages in the patient's journey – and however important the transition from hospital to home – continuity of care for some people needs to be for a long time, and in some cases for life. What these comparisons between case studies also underline, however, is the difference between the care for someone who has had a stroke, which is daily and hourly over several weeks and months. Inevitably this proximity forges a personal relationship between patients and staff which is hard to replicate in learning disability services, where professionals' contact with service users and their families is comparatively sporadic and fairly distant.

### **6.3 Continuity of care: the inter-professional context**

In the next two sections we focus on the ways in which inter-professional and inter-organisational working influenced continuity of care. For patients, service users and carers, the impact of interventions is typically experienced as a set of activities of professionals, both individually and as members of teams. Generally, it is by making a judgement on the behaviour of professionals that patients and service users come to form a view on the degree of continuity of their care. The more complex the intervention, the greater the number of professionals involved, and the greater the number of interfaces to be managed, then the higher the likelihood of discontinuities. The concept of inter-professionality has been coined to describe this situation (Hudson, 2002).

As with the notion of user involvement, the idea of multi-disciplinary team working has become *de rigueur* in policy and practice exhortation – the Green Papers on children and young people (Chief Secretary to the Treasury, 2003) and adult social care (Department of Health, 2005) both lay great stress on the development of co-located teams of professionals working in a co-ordinated fashion with users who have complex problems that straddle traditional professional boundaries. However, the research messages on the likelihood of attaining effective team working are not especially encouraging, with problems identified around such matters as professional identity, professional status and professional accountability (Hudson, 2002).

This has resulted in widespread scepticism about the way in which the inter-professional venture has been undertaken. Calling professionals a team has, according to Ovretveit (1996), 'become a way in which managers and planners avoid the real problems and work needed to co-ordinate an increasingly complex range of services to the community' (p. 168). According to Jones Elwyn *et al.* (1998), 'There are so many factors which militate against team working that the team is in danger of becoming an unmanageable arena of professional conflicts struggling to provide an ever fragmented service' (p. 191). For Carrier and Kendall (1995), none of this should come as a surprise, since inter-professional working implies the sharing of knowledge, respect for the individual autonomy of different professional groups and administrators, the surrender of professional territory where necessary, and a shared set of values concerning appropriate responses to shared definitions of need. As the authors note, 'professions are likely to find this an ambitious and demanding agenda' (p. 18).

One manifestation of team working involves an identified professional who has the responsibility to co-ordinate service providers, and to be accessible to the service user. This is not a new idea. The desirability of having a key worker has been recognised for a long time, especially where this relates to some co-ordinating process such as care management. Again, the respective Green Papers have focused strongly on this issue – with a lead professional in the case of children and young people (Chief Secretary to the Treasury, 2003), and a range of possible models for adults including a person-centred planning facilitator, a care manager, care navigator and care broker (Department of Health, 2005, para 4.40).

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These general concerns and issues were also an important feature of our case studies, with the role of specific co-ordinators being crucial. Several key questions therefore need to be raised about our study data. First, are there clear objectives that are understood and acted upon by all of the professionals involved in the interventions? Secondly, is there an identifiable 'team' that is properly accountable and effectively co-ordinated? And, are there specific co-ordinating roles assigned to individuals, and are these fulfilled effectively?

Our case studies reveal both similarities and differences. On the whole, team working and co-ordination were more elusive in the case of learning disability than stroke. In the case of stroke services there are repeated references in almost all the guidance to the importance of an identifiable specialist stroke team, working in a Specialist Stroke Unit. The exact composition of the team (as with the exact constitution and location of the unit) is less clear-cut. Unsurprisingly, medical, nursing and therapy staff are always listed. What is less clear is what is the range of appropriate therapists and whether two other disciplines – social work and clinical psychology – are also vital in ensuring that the specialist team can provide an integrated stroke service across the whole patient journey. In terms of the principal focus of this case study – upon the hinge point of transition/transfer from hospital into the community – the social work input is crucial. Some of the guidance (including the European Stroke initiative) spells out the importance of the social worker role in ensuring integration and continuity of care across this point of transition.

In the three localities in this study the involvement of social workers in the stroke team was an issue of concern. It was universally the view among hospital-based health staff that a continuous social work presence – in terms of attendance at MDTs and acting as a ward link – would enhance the stroke team's work, especially but by no means exclusively around hospital discharge. Social services, however, reported facing severe resource constraints, recruitment and retention problems and competing 'bids' for a comparable social work attachment to other teams for other conditions. Part of the answer – as in Darlington and Lancashire – is to develop generic Hospital Discharge Teams. These, it was generally agreed, had the advantage of being hospital-based and having a clear focus, but they cannot necessarily acquire a condition-specific expertise.

All the evidence shows that, nationally, there is almost no clinical psychology input to specialist hospital stroke services. South Tyneside is among a minority of localities nationally to have a clinical psychology input, and even here it was half time. The clinical psychologist was highly valued by fellow staff and by patients and carers in South Tyneside. The role was badly missed in Lancashire and Darlington. The absence of community-based clinical psychology was also important, especially given the prevalence of depression among people with strokes over long periods after leaving hospital.

There were two other main concerns about the constituent elements of an integrated specialist stroke service. The first was the shortage of other disciplines, notably the virtual absence of speech and language therapy within the community, a shortage of occupational therapists, which can seriously delay hospital discharge when home visits are not undertaken, and shortages of physiotherapy in the community, which had significant effects upon patients' rehabilitation. A second main concern – except in South Tyneside – was the absence of a Specialist Community Stroke Team (and even in South

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Tyneside there were concerns about the extent to which a very small team was stretched). The absence of such teams leads to a reliance upon generic community teams, which by definition lack specialist stroke expertise. At times people were kept in hospital longer than they would have been if a specialist community resource existed, because they did not want patients handed over to a generic (and also stretched) community resource.

It was also evident that on occasions hospital-based staff were keen to avoid multiple transitions for patients; that is, where possible they should go from hospital to home (or to a care home). Sometimes intermediate care would seem appropriate; but on the grounds of continuity of care alone hospital staff disliked patients being re-assessed by social services staff at the time of discharge to see if they should have a period of intermediate care prior to going into long-term care. We should not overstate the extent or the frequency of this sort of dispute, but it does reveal important differences of professional views about risk, patient potential and appropriate destination. These differences of view, it was widely suggested, would be reduced if the investment was made in well resourced inter-agency and inter-professional stroke teams operating across the whole patient journey.

It is important to note two other aspects of inter-professional working which significantly affect patients' perceptions of continuity of care. The first was the way in which teams worked on any unit or in any service. From a patient's point of view there must be an impression of individuals working as members of a single team, and not as representatives of separate professions merely working *in* a team. We found evidence of such good inter-disciplinary working, not merely multi-disciplinary working, in each of the localities. A second aspect is the importance of the role played by professionals with a specific co-ordinating remit. In all three localities this was a role played by stroke specialist nurses. Although none was titled stroke co-ordinator, the stroke specialist nurse in South Tyneside was *de facto* stroke co-ordinator across the key hinge points. The remit was narrower in Lancashire, with organisational complexity, geographical dispersal and size of service restricting the stroke specialist nurse's work as co-ordinator to the acute setting (i.e. Blackpool Victoria Hospital). In Darlington the stroke specialist nurse played a similarly narrower role, though here partly because the post is only a half-time one. In these two localities the co-ordinators were effectively able to promote continuity only within their own parts of the system. In all three cases the stroke specialist nurse acted as the co-ordinator of fellow professionals – outside as well as within the specialist stroke service – but only in South Tyneside was this co-ordination between detailed operational practise and strategic planning. Only here did the *de facto* stroke co-ordinator have the scope and ability (and legitimacy and status) to act as the sort of reticulist we discussed above.

In the case of learning disability services we identified two potential sources of such personal-professional continuity, namely the Connexions PAs and the Transition Workers normally appointed within adult social care. Not only were there questions about the precise role and workload of the PAs, but whether, if it was to be specialist rather than generic, individuals had sufficient training to understand the specialist services. Whereas there was no doubt about the specific focus of the Transition Workers there were some doubts about the balance between operating as co-ordinators or caseload managers, and also

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about links between their operational practice and strategic planning. Importantly, too, there were some questions about the nature of the links between these two posts: links which, unsurprisingly, often depend for success upon inter-personal relationships rather than inter-professional roles and remits.

It is worth stressing again here the difference between learning disability and stroke in terms of the proximity of professionals to patients/service users and their families. Inter-professional working in the case of someone who has had a stroke involves a physical closeness which initially must be minute-to-minute and then becomes hourly and daily. Even if the period of acute care and rehabilitation lasts for 3 months constancy of care is important. It is also care in which the notion of the transition or transfer has an immediacy that is apparently absent in the field of learning disability. This immediacy in stroke services means that service professionals undertake transfers as a personal and sensitive handing-over from one to the other. (Although, of course, as we have seen this often seems to patients and carers less personal and less sensitive than they would wish.)

In contrast, the continuity of care for people with a learning disability is dispersed and episodic. This in no way lessens the need for inter-professional working: indeed in some respects it increases the need. As it was, we found evidence of a gulf between children's and adult services in both social care and healthcare. In the former case the most frequently cited explanation for the gulf between children's and adult services revolved around differences in approach and culture. Thus whereas there was a general view that adult (social care) services embraced corporate working, children's (education) services were more insular. This was a difference said by some to be reactive and short term in children's services and proactive and longer term in adult services. This cultural dissonance appears to reflect the view that the job of education services is to get children to the end of their school career, without properly engaging in a discussion about what happens at the other side of the transition to life after school. As with social care, there was a problem in health services about handing over children from paediatric health to adult health services. The loss of services typically seemed abrupt and was not explained to families. Health support was reduced in nature and range and regular appointments with known health professionals simply ceased, 'to be replaced by an injunction to contact services as and when help was needed'. Where is the equivalent of the handover from one professional to another that we saw evidence of in stroke services? Where is the personal introduction from one healthcare professional to another? As if this were not bad enough, adult health staff shortages mirrored the shortages among paediatric services.

One other important recurring difficulty across the study localities was the poor attendance of professionals at transition planning reviews. This was explained partly by workload pressures and – in a striking echo of the problems in stroke services – was said to be explained partly by staff shortages in the fields of occupational therapy, speech and language therapy, physiotherapy and educational psychology. Unquestionably it was partly also due to perceived differences in priorities at times and to disputes about whose responsibility a particular young person was.

### **6.4 Continuity of care: the inter-organisational context**

Public services have been subjected to a range of modes of governance in the post-war period, each associated with service re-focusing and organisational upheaval. Broadly, three phases can be identified:

- separatism, where each agency plans and delivers its own contribution in isolation from the contribution of others;
- competition, where purchasing is separated from providing, and providers are placed in a competitive relationship to one another;
- partnership, where agencies participate in specific and *ad hoc* collaborative relationships of varying degrees of complexity.

Despite rhetoric to the contrary, the relationship between these phases is not one of displacement but of aggregation – different modes of governance have developed in complex and sometimes contradictory ways, and now overlap with one another. In our case studies, the inter-agency partnership imperative co-existed with other modes of governance, notably the rise of policies on competition and choice from 2000 onwards, as detailed in Section 3.

In some of our earlier work (Hudson *et al.*, 1999) we identify 10 stages of collaborative endeavour. The notion of stages implies sequential activity, and although such a logic can be identified, it would be wrong to suggest that there is some iron law of collaborative endeavour through which agencies must dutifully process – some may have made more progress on later stages than earlier ones, or may find themselves losing some of the success they may have gained at any particular stage. The process could be in need of repeated attempts to even begin, and thereafter is likely to be iterative and cumulative rather than merely sequential, with a large element of learning by doing. For these reasons we prefer to refer to components rather than stages. The 10 components are identified in Box 3.

#### **Box 3 The 10 components of collaborative endeavour**

Contextual factors: expectations and constraints

Recognition of the need to collaborate

Identification of a legitimate basis for collaboration

Assessment of collaborative capacity

Articulation of a clear sense of collaborative purpose

Building up trust from principled conduct

Ensuring wide organisational ownership

Nurturing fragile relationships

Selection of an appropriate collaborative relationship

Selection of a co-ordination pathway

It is not our intention here to comprehensively review our case-study findings against each of these criteria, but rather to highlight some of the most relevant factors within and across the two studies. In doing so, we are



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interested in two key questions. First, are the separate agencies aligning or integrating their policies, processes and procedures in such a manner that service users experience care seamlessly? Second, is the inter-organisational environment sufficiently stable and simple to encourage local partnering to flourish? Negative answers to these questions will constitute the hinge points at this level of understanding and provide the basis for pursuing further questions at the level of central–local relations.

In Sections 4 and 5 we emphasised the extent to which organisational turbulence produced a context in which it was difficult for local partnership working to flourish. Major restructuring of local NHS organisations in 2002 entailed loss of key staff, of organisational memory and of momentum. It also invariably entailed uncertainty for staff, reconsideration (and often re-ordering) of aims and objectives, and a fracturing of professional networks and partnership arrangements. In this context stroke service planning and operational service delivery were inevitably affected. At the level of front-line services the effect was felt in posts and funding being withdrawn or delayed. It meant delays in agreeing care pathways or joint protocols, and it had an effect upon the degree to which services were joined up across redrawn organisational and professional boundaries – and, thereby, an effect upon the continuity of care for individual patients.

This is not to suggest that turbulence paralyses local service delivery. It does not. Service professionals and managers work around the problems they encounter. Nevertheless, they are barriers which compound the likelihood of discontinuities occurring at organisational and professional boundaries. On the evidence of the contrast between South Tyneside and Lancashire (Fylde and Wyre) in particular, but Darlington too, there is little doubt that stability helps to promote joined-up working, integrated service planning and provision and – by extension – continuity of care for patients. Continuity is also more likely with a smaller number of partners. It is worth repeating a point which is often made, that conterminosity and co-location do not guarantee partnership working. They are, however, extremely important building blocks. Moreover, the problems of more complex and turbulent contexts were summed up by the senior health-service manager in South Tyneside who said, ‘people don’t like change, so if you are dealing with a multiplicity of partners you just get an exponential growth in the potential blockages’, and that the micro management, ‘required for complex cultural problem-solving across many organisations again becomes exponentially complex’.

Notwithstanding these points, there were clear examples of organisations working within reconfigured partnership structures around NSF Standard 5 (and also in South Tyneside and Darlington within the broader umbrella of LSPs) to agree stroke service models, priorities and funding. Once again, however, this was easier in South Tyneside than in the complex circumstances of both Darlington and Lancashire, where differing funding priorities among local PCTs were having a discernable effect upon investments in stroke service development.

In the field of learning disability there has not been the same major restructuring, but there has been a proliferation of legislation and guidance with attendant requirements to establish new local partnership arrangements. As in stroke-service development – and as referred to above in terms of the new breed of Connexions PAs – there are real issues about how far service

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development for individual services and conditions can be internally coherent and joined-up without a specialist organisational framework and focus. Thus, however promising the Connexions Service is as a framework for addressing the point of transition from childhood to young adulthood, it is a generic service. Moreover, it has been given an extremely demanding partnership remit (across a plethora of local organisations and services), with some confusion about its precise role and with limited funding.

Even where there is a specific, specialist organisational focus, such as the Learning Disability Partnership Boards, we found problems of limited remit and scope (they are responsible for adult services and can neither hold budgets nor appoint staff), limited membership and sporadic attendance. This state of affairs appears to reflect two underlying issues. The first is the priority attached locally to learning disability services – although this was an explicit local priority in South Tyneside – and, within learning disability services, the priority given transitions and transition planning. Second, there was the scale and complexity of the task in the expanding universe of those responsible for joined-up planning and delivery of learning disability services. The available instruments for securing co-ordination and coherence – including JIPs and the Health Act flexibilities – appeared to be little used or ineffectual. The problems taken together, as we said earlier, 'suggest that the scale and complexity of transition is currently defying structural attempts to introduce coherence and purpose...in these circumstances transition is not addressed in a holistic way'. Our blunt conclusion to the learning disability case study was that 'the key feature of transition seems to be discontinuity rather than continuity'.

Poor communication seems to us to be at the heart of the matter. Communication problems were of various types. The most mundane (but non-trivial) included letters going astray or arriving late, but it was also withheld, went 'missing', or was confusing or conflicted with information or advice from elsewhere. Good communication and good information were not the norm. In some ways this is difficult to understand. The fact that a young person with a learning disability is approaching a particular age – and, therefore, needs transition planning – would seem hard to miss. Unlike the onset of stroke, which is characterised by suddenness and general unpredictability, a child's age is certain and future birthdays therefore utterly predictable. The transition from childhood to adulthood affords the luxury of lengthy, well-considered planning. But this requires information to be accurate, available and shared. The evidence from this study was that too often it was inaccurate, unavailable and not shared.

In part this can be traced to deeper organisational fragmentation between children's and adult services of the kind discussed in the previous section. These were what the Social Services Inspectorate in 2003 called 'demarcation disputes between different council and health departments'. There was also what one community nurse referred to as 'a number of interfaces with social services, but no integration'. As with stroke services, the effects of such organisational fragmentation may be greater where only generic rather than specialist support is available.

### **6.5 The context of central–local relationships**

The role of central government in our studies was both strong and weak. It was strong in the sense of the large volume of legislation, regulation and good-practice guidance emanating – though often in a disconnected way – from a plethora of relevant central bodies. It was weak in that much of this material was either narrowly interpreted or ignored with impunity. The message many of our respondents drew from this experience was that learning disability and stroke were simply not priorities at central level, and that local decision-makers were well aware of this situation. It is not a question of these local decision-makers having no interest in, or concern about, learning disability or stroke. Rather, they were judged at national level on other priorities and achievements.

It is important to locate our two case-study domains within the broader picture of central–local relations in the UK (Jones, 2003). Taking a relatively recent time scale, one could say that in 1997 the UK was the most highly centralised state in Europe but that since then some degree of decentralisation has occurred. One view is that between 1997 and 2001 the Labour Government maintained this centralist approach, but that by 2001 it was recognised that a more decentralised model was required, one sometimes described as new localism. However, an alternative view is that this new localism remains an essentially centralist approach, with central government itself divided over its attitude to localities. Some parts are keen to give up controls and allow more local discretion, others less so.

There have been some recent shifts towards ostensible decentralisation across local government (through the development of Local Area Agreements) and the NHS (through budgetary devolution to PCTs), but it remains the case that all local bodies still have to work within the constraints of a national policy framework, centrally mandated targets and a centralised system of performance management, assessment and regulation (Lewis *et al.*, 2003). The view of Jones (2003) is that:

*Society can learn little from centralisation about how to deal with the horrendous and apparently intractable social problems of today, but decentralisation allows local experiments to meet local needs. Some will fail and some succeed, and from this laboratory of innovations society can learn what works best, where and under what conditions.*

(p.10)

Respondents across local government, the NHS and elsewhere tended to be of the view that their hands were tied in dealing with many of the issues central to our case studies. This was partly because the key agencies were being judged upon other issues, partly because decentralised funding was in reality already committed to existing expenditure patterns, and partly because the complexity of the issues seemed too intractable, intellectually and practically.

Our data present a mixed picture, with the centre apparently prescribing desired activities in some detail, but placing a higher priority on other matters. Certainly, not all of our respondents thought they had the resources, authority or capacity to make significant and lasting improvements. In the case of stroke services there were several clear messages across the three localities about the effects upon local service planning and development of

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central government guidance, priorities, funding and performance management. First, there was near unanimity among service professionals and managers that stroke is accorded too little priority as compared, for example, with CHD. CHD was the subject of a separate NSF, whereas stroke was 'buried' in the NSF for Older People. CHD has attracted substantial funding to match its status as a national priority. Stroke has had no comparable injection of funds. As a consequence local CHD services, but not stroke services, have seen considerable investment, not least in additional staffing. National priorities, it was said, largely dictate local priorities. Therefore, while meeting NSF targets is an important local priority it is less important than meeting even more prominent national targets on access, waiting times and 'balancing the books'. Thus, whereas a 'red light' on missing the NSF Standard 5 target for having a Specialist Stroke Unit was important locally, it was less important than missing waiting-time targets.

It should be said, however, that many interviewees in the study commented on the now taken-for-granted nature of NSFs. Whatever their perceived shortcomings (e.g. in terms of stroke being wrongly 'placed') the frameworks were acknowledged as precisely what they are, frameworks which set benchmarks for local service design. As a set of guidelines they were important not least because they could be held up locally as requiring more than just token consideration. They do, in this sense, act as a serious prompt to local service development. In some cases they were used as a stick with which to beat local service managers, who were reluctant to invest in service development. It has to be said, however, that another facet of wider performance management frameworks is the ability for such managers to reply – as we have seen them do – that outside the NSFs are even more immediate priorities to which are attached even bigger Government sticks.

In the case of learning disability services we have already noted the raft of legislation, guidance and exhortation from the centre. Statements of special educational needs, transition plans and reviews are mandatory, not mere exhortation. Among other things guidance makes it clear that transition planning should be seen as a broad and continuous process – of which the plan and reviews will be intermittent outputs – either side of the point of transition. In other words, transition planning is not simply about leaving school, but about moving to adult life generally. But here, again, there is a sense in which the framework of national guidance is at odds with the practice of service development. Just as stroke guidance appeared to many to sit oddly in an NSF for Older People so guidance on transitions from childhood to young adolescence, and then to adulthood, sits uncomfortably in an NSF for children and young people.

The evidence from our study is that there is plentiful guidance on partnership and service integration, and policy instruments to secure partnership working across agencies and professionals, and across children's and adult services. However, the plethora of guidance is simply not joined up, and what is done does not reflect what is required by users and carers on the ground. All too often the transition appeared to carers not only to be unplanned and unco-ordinated but also accidental. As in stroke services, organisations and professionals at a local level face a context not only of considerable inter-organisational flux but of competing priorities and shortages of staff. Whereas none of the service professionals or managers across the fieldwork

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sites – in both services – argued that more money from central government alone was the answer to a truly joined-up set of services, most were clear about two things. First, adequate funding is essential to the development of integrated services which deliver continuity of care for patients and service users. Second, they believed that funding, legislation, guidance and performance management needed to be far better joined up. It is to this last point that we now turn.

### **6.6 The broad context of joined-up government**

At the start of this section we explained that our approach was to start with service delivery and work upwards towards the level at which national policies are formulated. At national policy level we can ask how far Government policies reflect a coherent understanding of the nature of joined-up delivery. In practice, we have found that many Government policy documents contain general statements about the need to improve the co-ordination of services. When the Labour Government came in to power in 1997, one of its concerns was with the perceived fragmentation of public services. There was fragmentation within services such as the NHS, and also across traditional organisational divides, for example, between health and social care. The *Modernising Government* White Paper, published in 1999 (Prime Minister and Cabinet Office, 1999), reflected this concern. It stated that:

*There are many barriers to providing services in the way people want them. The separation of government into different units, though necessary for administrative purposes, often means that people do not receive services in a co-ordinated way or that they receive multiple visits from different agencies. Individual agencies' performance targets and budgets can get in the way of them working together. Audit and inspection processes may hinder cross-cutting work... Different government offices are often situated a long way apart from one another, and attempts to bring them together can be hampered by rules and regulations. And the multiplicity of administrative boundaries across the country can lead to inefficiency, complication and confusion.*

(Prime Minister and Cabinet Office, 1999, Chapter 3, para 3)

This analysis is not new, and policies over earlier decades had been expressly designed to promote better partnership working. It seems fair to say, though, that there was a new rhetoric in this area. In the last 5 years policy documents have been studded with references to care pathways, networks – as in NHS Collaboratives – and whole-systems working.

The important point here is that the Government has used its various policies to give permission to people on the ground to pursue more joined-up and person-centred service delivery. For example, a 2003 policy document, *Discharge from Hospital: pathway, process and practice* (Department of Health, 2003d) describes whole-systems working in these terms:

*A 'whole system approach' is one that recognises the contribution that all partners make to the delivery of high quality care. Whole-system working does not have restrictive service boundaries – it puts the individual at the centre of service provision and responds to their needs. ... The whole system is not simply a collection of organisations that need to work together, but a mixture of different people, professions, services and buildings which have individuals as their unifying concern and deliver a range of services in a variety of settings to provide the right care in the right place at the right time.*

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Thus a whole-systems approach appears to be one where all parties involved in a person's care should co-ordinate their work and provide services on the basis of each individual's needs.

The evidence presented in this report, for both service contexts, suggests that giving permission is not enough. There are problems that can be traced, at least partially, to national policy level. The lack of resources – perhaps most evident in the fact that stroke is not a national priority for funding in England – has clearly had an effect on the quality of services provided on the ground. The testimony of several people we interviewed further suggested that there are tensions between the exhortations to engage in whole-systems working and the need to achieve performance targets.

Finally, whereas the policy rhetoric is clearly in sympathy with many of the observations that we have made about continuity of care, our sense is that it is currently too abstract to be meaningful to people on the ground. In other policy areas, such as in intermediate care, there is guidance which helps to flesh out the nature of intermediate care, and in sufficient detail to give service providers and managers a reasonable idea of the expected direction of travel. This detail is provided in the case of learning disabilities – but as we have observed the problems lie elsewhere. In the case of stroke care, it is at times difficult for people on the ground to interpret the high-level statements about joined-up working;

### ***6.7 Conclusions***

In this report we have presented detailed accounts of the experiences of a number of individuals and their carers, in both stroke services and learning disability services. Ultimately, we believe that continuity of care is a phenomenon that can only really be understood from the service users' perspective. The accounts have revealed some important resonances between users' experiences of the two conditions. For example, there are points where key staff are simply not available, and there are communication breakdowns between the various parties involved. They have also revealed differences in the experience of continuity, which stem in part from the very different time courses of the conditions. Continuities and discontinuities in stroke care are apparent over days and weeks, whereas younger people with learning disabilities experience them over weeks, months and years.

As we have climbed the ladder in the course of this section, the contextual factors which help to explain the reported experiences of continuity and discontinuity of care have been highlighted. It is difficult to escape the conclusion that many of these factors are structural in nature. There are staff shortages which have not been addressed at national or regional level over decades. The difficulties of linking social workers into stroke teams reflect the long-standing structural divide between health and social care, commented on in official reports over the last 50 years, up to and including the second Wanless report. These problems, which can have a marked – one might say obvious – affect users' experiences of care and sit uneasily with the current rhetoric of joined-up and whole-systems working. Those terms may be relevant in services where the increases in funding have led to fully staffed

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and well managed teams, but neither of our services has benefited directly from the increases in funding of public services in the last 5 years.

Our analysis has, in the nature of this type of report, tended to highlight the times and places where discontinuities occur. But it cannot be stressed enough that, in stroke care especially, we have witnessed care that is well co-ordinated within any one phase of care, and continuous over time, so that treatment and care following a stroke were handled thoughtfully and sensitively over a period of months.

We are left with the question that we started with: what is continuity of care? We think that the answer comes in two parts. The first is that continuity of care only makes sense – and only really matters – from the perspective of the service user. This study has shown that continuity is as much about parallel events as events occurring in series over time. That is, if one were to take a snapshot at any one point in time, one would expect to find pathology tests being undertaken at the same time as therapist assessments, or education and social services communicating about the next steps in the transition of a younger person with a learning disability. Equally, we have reported both good and bad experiences at the hinge points we studied which are the successes and failures of processes occurring in series.

The second part of the answer concerns the things that are continuous. We have already stated that the patient or service user is central to any discussion. More generally, we can say that continuity of care is about continuity of resources, of communications, and of the co-production of care. As patients/service users go on a journey through care, they attract resources, and their presence leads to communications, both between professionals and between professionals and patients/service users. Over and above these communications, our evidence shows that continuity rests on co-ordination between patients/service users and service providers. Put more mundanely, continuity is in part about effective co-ordination between patients/service users and the care system. Conversely, discontinuities in care – whether these are desired or undesired – can be defined as discontinuities of resources, communications and co-production.

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## **Appendices**

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### **Appendix 1 Moving on after a stroke: a structured literature review**

#### **Introduction**

In England and Wales each year, about 110 000 people have their first stroke and 30 000 others have a second or subsequent event (Department of Health, 2001). Stroke is the third most common single cause of death in the UK and other developed countries (Department of Health, 2001). The risk of recurrent stroke within 5 years is between 30 and 43% (Intercollegiate Working Party for Stroke, 2004). Stroke-related illness has been estimated to take up 16 000 NHS beds every day (Department of Health, 2001), and the cost of stroke to the NHS is estimated to be over £2.3 billion (Department of Health, 1996). It is the largest single cause of severe disability in England and Wales, with over 250 000 people being affected at any one time (www.stroke.org.uk). A 30% increase in the numbers of patients affected by stroke has been predicted between 1983 and 2023 (Malmgren *et al.*, 1989).

Stroke is often a devastating event for an individual and a time of great change for family and friends, and typically requires wide range of interventions, with the details of the services needed varying from person to person. There is good evidence that outcomes are improved if the main part of acute care is provided by a specialist unit (Kalra *et al.*, 2000; Stroke Unit Trialists' Collaboration, 2002) and the NHS in both England and Scotland is implementing stroke units in all acute hospitals (Department of Health, 2001). This said, many patients are still cared for on general wards (Rudd *et al.*, 2001a).

#### **Methods**

This study was not funded to undertake a formal systematic review of the literature, but it was clearly necessary to identify what is known and not known about continuity of stroke care. This Appendix sets out the results of a structured literature review, which was initially undertaken in 2002 in the early stages of the project, and updated in the summer of 2004. Searches were conducted on the following databases: Cochrane Library, HMIC, Medline, Applied Social Sciences Index and Abstracts, Sociological Abstracts, Social Services Abstracts, PsychoInfo and Web of Science (Social Science Citation Index).

Using a number of alternative terms for stroke, such as cerebrovascular disease, each database was searched using these terms in conjunction with one of a number of terms indicating a focus on discharge or rehabilitation.

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Details of the search strategies used for each database are shown in Table A1 below.

**Table A1 Search strategy for the structured literature review**

Database(s)	Search strategy
Sociological Abstracts Social Services Abstracts Applied Social Sciences Index and Abstracts	(stroke rehabilitation or ((discharge plan* or patient discharge* or hospital discharge*) and stroke)
PsychInfo	1 exp *Cerebrovascular Accidents/ 2 *REHABILITATION/ 3 continuity of care.mp. 4 transitions.mp. 5 exp Hospital Discharge/ 6 exp Long Term Care/ 7 exp DEINSTITUTIONALIZATION/ 8 community care.mp. 9 3 or 4 or 5 or 6 or 7 or 8 10 1 and 9 (15)
HMIC	#18 #16 and #17 (97 records) #17 stroke (934 records) #16 #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 (7904 records) #15 discontinuity of care (6 records) #14 patient discharge (1371 records) #13 patient outcome* (1918 records) #12 transition* (1495 records) #11 integrated care (247 records) #10 shared care (302 records) #9 inter professional (129 records) #8 seamless service (59 records) #7 seamless care (63 records) #6 multi agency working (33 records) #5 care plan* (2018 records) #4 horizontal integration (4 records) #3 vertical integration (31 records) #2 continuity of patient care (97 records) #1 continuity of care (489 records)

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Medline	1 Cerebrovascular Accident/nu, co, dh, dt, rh, th
	2 Cerebrovascular Disorders/nu, co, dh, dt, rh, th
	3 transitions.mp.
	4 *Continuity of Patient Care/
	5 *Patient Transfer/
	6 *Patient Discharge/
	7 *REHABILITATION/
	8 *Long-Term Care/ or *Deinstitutionalization/
	9 1 or 2
	10 3 or 4 or 5 or 6 or 7 or 8
	11 9 and 10

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Cochrane Database of Systematic Reviews	Using keyword stroke
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During the first phase of the review, search output (titles and abstracts) was inspected by one of us (M.R.) to select articles to obtain in full using the following criteria:

- a description of the process of care surrounding or after discharge, from a patient, carer or professional perspective; or
- reports of a specific innovation or method of practice for co-ordinating the work of two or more professional groups or agencies before or after discharge; or
- a discussion of issues or concerns about inter-professional or inter-agency work for stroke.

The following types of article were excluded:

- randomised controlled trials and other evaluations which did not appear to describe the process of inter-professional or inter-agency work;
- economic evaluations;
- care processes specific to a non-UK healthcare system or language of publication not English.

In addition to articles obtained directly from the search results, articles in the background and grey literature were identified by discussions with colleagues. The reference lists of selected papers were also examined to identify further articles of potential interest.

In 2002, selected papers were read by one of three team members (M.R., B.H., J.K.). No systematic abstraction of results was attempted, but a note was made of particular results or discussion of continuities/discontinuities in care, the reasons for their occurrence and their effects on subsequent process and outcome. In July 2004, a similar process of searching and abstraction was undertaken by one author (T.D.) to update the review. The only significant difference in method was the inclusion of the search term 'community rehabilitation' within the various search strategies, since it had become clear in the intervening period that this was a term in common use in the literature.



### **Results**

After removal of duplicates, 113 papers were identified from the initial searches. A further six were grey literature/background suggested by colleagues, and to date 30 have been identified from the reference lists of other papers. Subsequent searches and suggestions by members of the consensus-development group led to the inclusion of a further 82 papers. Findings from the literature are presented in two parts, as follows.

- 1 What are the issues? Identification of the critical hinge points in the journey from specialist stroke services to long-term care or recovery.

This provides an operational definition of continuity of care for stroke. There are two contrasting types of evidence which provide information on this subject. First, the accounts of individual patients and their carers about the journey through care and the significant events on the way. Such evidence is based on one case or, in the case of professional care-givers, a small number of individual cases. In many cases, description of what was not done, or not done properly, may overshadow what is perceived as effective and appropriate and so may be taken for granted. The second type of evidence is evaluation of the impact made by a specific intervention at a fixed point in the recovery process across a representative sample of patients; for example, the effect of domiciliary occupational therapy following hospital discharge (Gilbertson *et al.*, 2000). One difficulty with this type of evidence is the assumption that because an intervention shows an effect on outcome there must have been a critical transition at the time that the intervention was applied – this may not be true. Another difficulty is the variability in how services are configured, which makes it difficult to generalise findings from one configuration to another (McKevitt *et al.*, 2000). There is a third type of evidence which uses a mixture of individual accounts and aggregate data, which may offer a solution, but this requires further discussion.

- 2 What are the current solutions? Descriptions of specific working practices or service models designed to expedite progress across the critical hinge points described above.

The strength of evidence that the rate of progress or final outcome really is better as a result of the proposed intervention may be weak or absent; many reports in this section are anecdotal or uncontrolled. Some randomised controlled trials have been undertaken to evaluate whole service models or specific interventions at critical points, but trials of specific interventions which have complex interactions with other parts of the care package are problematical (Wade, 2001).

### ***What are the issues? Identification of the critical hinge points***

In general, the literature discovered for this review does not make explicit statements about which points in the journey through care are critical, or how inter-professional and inter-organisational partnerships may help patients to progress through these points. This contrasts with the literature identified for the other tracer condition in our study (see Section 5), where discussion of the requirement for partnerships is prominent. Under these conditions, the

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issues need to be identified indirectly. This section highlights both general and specific findings which help to do this.

General findings:

- the status of stroke and stroke services within the healthcare system,
- the variability of services,
- tensions between professions,
- the impact of stroke on patients,
- what does continuity of care mean to patients?

Specific findings:

- the discharge process,
- the long-term prognosis for older people with stroke,
- the role of carers and families.

### ***General findings***

#### **The status of stroke and stroke services within the healthcare system**

A qualitative study of healthcare professionals and managers concerned with stroke (Kaufman and Becker, 1986) in California in the late 1980s reported that the healthcare system devalued rehabilitation, that stroke rehabilitation was perceived to be separate from acute care medicine and that stroke was a geriatric problem. Whereas this study may be discounted in terms of its age and location, it establishes an ideological divide between stroke care and acute care which may still be relevant now. Geriatric medicine has traditionally been low on the ladder of professional esteem within medicine, so stroke rehabilitation may be doubly undervalued professionally.

Recent advances in stroke medicine may have begun to change this pattern. In the UK Petty referred to it being a 'little more fashionable to care for stroke patients' (Petty 1998), and the National Service Framework (NSF) for Older People (Department of Health, 2001) includes a Stroke Standard. However, attention appears to remain focused on inpatient care. The only mention of stroke within the 2003–2006 NHS Priorities and Planning Framework (Department of Health, 2002) is the target that by April 2004 all general hospitals caring for people with stroke would have a specialised stroke service. Whereas there is recognition of the importance of the discharge process and transfer of care (see for example the national clinical guidelines; Intercollegiate Working Party for Stroke, 2004), there is a lack of emphasis and consideration on the long-term issues that people who have had strokes need to deal with. It has been argued that jointly agreed stroke care pathways need to be developed for the long-term care of patients and their carers, and which, critically, do not just finish on hospital discharge (Department of Health, 2002).

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### **The variability of services**

Perhaps because of the relatively low status ascribed to stroke services, there is great variability in many aspects. The Biomed II study across 14 European countries (Wolfe *et al.*, 2002) has demonstrated this internationally. Three overall types of configuration, within which there are many detailed variations, were described (McKevitt *et al.*, 2000):

- transfer from initial intensive care or acute admission unit to an on-site specialised stroke unit, then to home or long-term residential care;
- initial care in a general hospital ward, followed by transfer to an off-site rehabilitation facility, then home or long-term care;
- direct discharge from general hospital to home or continuing care.

A taxonomy for describing the differences between facilities has been developed (Hoenig *et al.*, 2000), and used to show a hierarchy of care in the USA, with the most intensive rehabilitation being delivered in specialist neurological units. The NHS might be expected to offer a more uniform pattern of care, but one of the main conclusions of the first national sentinel audit was that care was 'disorganised and haphazard' (Rudd *et al.*, 1999). There were inexplicable regional variations, such as the rate of institutionalisation after stroke varying from 10% in the North Thames region to 27% in the north west (Rudd *et al.*, 2001b). The second round of the audit in 1999 (Rudd *et al.*, 2001a) showed some improvements; even so, only 26% of patients spent more than half of their time in hospital on a specialised stroke unit. Only 57% of the 157 responding trusts had a specialist team for stroke and in only 25% did a social worker attend team meetings on all wards.

### **Tensions between professions**

Whereas the necessity of stroke rehabilitation being a multi-disciplinary activity appears to be undisputed, this does not mean that there are not tensions between the different healthcare professionals involved. Although most clinical staff pay lip service to the principles of interprofessional working, there is evidence that the basic concepts are often poorly understood. As one nurse whose ward was converted from continuing care to rehabilitation stated:

*...it is so much easier and quicker to do things for patients than to stand and watch them struggle.*

(Grylls, 1998)

A postal survey of 12 nurses working as stroke co-ordinators in north west England were noted as having

*...limited capacity for the provision of an overarching perspective in stroke co-ordination that spans the entire course of recovery from stroke. Such a strategy might be highly effective in reducing the anxiety associated with hospital discharge and maintaining therapeutic relationships in order to plan and implement effective care support and teaching into the long-term.*

(Burton, 1999)

A number of potential barriers to inter-professional team working have been identified, including professional jealousies and role boundaries, perceived

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loss of autonomy and threat to professional status, lack of knowledge and unrealistic expectations of the role of other professionals, and increased defensiveness when 'pushed' to work as a team (Gibbon *et al.*, 2002). The perceptions held by each professional group of the role of colleagues are often negative and can be quite distorted.

Nurses, for example, do not feel that their role in the rehabilitation team is sufficiently acknowledged. An interview study in one rehabilitation ward, for example, concluded:

*...until the vital role of nurses in rehab. work is recognised...the nursing role will continue to be devalued and nurses will go on experiencing low personal and professional self-esteem.*

(Jones *et al.*, 1997)

A series of unstructured interviews with stroke patients and their carers on four general medical wards in South Tyneside concluded:

*The issue of continuity of care and continuity of carers becomes even more complex when viewed in a multi-professional context... Tensions and conflict between professional groups are well documented in terms of negotiation of roles in rehabilitation.*

(Close and Procter, 1999)

Practical obstacles such as shortages of personnel and time to attend team meetings, high staff turnover, physical separation of line management and professional development structures have all been observed (Gibbon *et al.*, 2002).

There are, however, also examples of successful inter-professional working arrangements within the literature. One study reported on findings from a series of ethnographic case studies of health and social services provision to adults recovering from a first acute stroke (Allen *et al.*, 2002a). Four case studies were carried out in two separate health authorities in Wales. The continuing care of each client as they progressed from acute to community care was explored for 6 months. The authors of the study were impressed with the willingness of providers of health and social care to work together to manage intra- and inter-professional and inter-agency boundaries, and with family carers to secure integrated care packages. There were many examples of proactive attempts to manage the health and social care interface and ensure a smooth transition from one service to another. The data did indicate the need for a clear identified lead at each stage of the caring trajectory, and where it was difficult to identify a key worker this had clear implications for service provision.

### **The impact of stroke on patients**

In considering the journey through stroke care, and the critical hinge points, it is worth considering briefly the nature of the impact of stroke on patients. This would facilitate consideration of, and give a more holistic focus to, how continuity of care is experienced by patients, and the development of appropriate and timely interventions.

Research in the field of stroke has tended to focus on the physical and functional impacts of stroke, taking little account of social and psychological impacts, processes of adjustment and how services are perceived and valued

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by those who use them. Moreover, research has tended to focus itself at a population level, and has not reflected the diversity of responses to stroke and the different interpretations and responses to services provided. This has limited current understanding of the full impact of stroke and therefore has limited the ability to respond meaningfully in the design of services for people affected by stroke. From the literature it is clear that those who have had a stroke face a wide range of problems, the intensity of which varies from individual to individual. Problems faced include (Becker, 1993; Ellis-Hill and Horn, 2000; McKevitt *et al.*, 2002; Hearn *et al.*, 2003; Murray *et al.*, 2003a):

- physical: loss/impairment of various faculties such as speech or mobility;
- cognitive: memory loss, inability to hold a train of thought;
- practical: as a result of physical difficulties, reduction of independence in activities of daily living;
- psychological: feelings of helplessness, dependence or depression, and loss of esteem/role, loss of confidence;
- social: curtailment or significant alteration of previous activities and relationships.

The nature of these problems for a particular individual will depend on a number of factors including severity of stroke, social support, an individuals' personality and the availability of services/interventions. These difficulties may occur in any combination and vary in importance over time. Recovery or adjustment after a stroke is an ongoing and continuing process that is likely to occur over a long period of time, if not the remainder of the patients' life.

There is a sociological literature which suggests that when people acquire a chronic illness, their known self is thrown into disarray, their sense of coherence/self-identity and continuity is undermined as individuals experience a differing relationship with their bodies, families and wider society. This has been termed biographical disruption (see, for example, Becker, 1993; Pound *et al.*, 1998a; Ellis-Hill and Horn, 2000; Faircloth *et al.*, 2004). People who have had a stroke face the task of integrating the physical and biographical disruptions that have occurred into their self-image so that a continuous sense of self emerges (Becker, 1993). The relationships between self, body, environment and daily life have to be redrawn. Routines of everyday life and the taken-for-granted assumptions that sustain them are disrupted and undermined.

There are examples, within the literature, of how stroke impacts on people's identity and sense of continuity (Becker, 1993; Pound *et al.*, 1998b; Ellis-Hill and Horn, 2000; Clarke, 2003; Murray *et al.*, 2003b). There are also some qualitative studies which detail how individuals adapt to these changes and consequently report a positive sense of well-being (Becker, 1993; Clarke, 2003). It is clear that adapting to the severe disruption caused by stroke is a lengthy and ongoing process with individuals having to redefine what is a possible life (Becker, 1993; Ellis-Hill and Horn, 2000). Furthermore, creating a sense of continuity and enhancing well-being is likely to be met by a series of setbacks (Becker, 1993). Adaptation can take many forms. For some, for example, repetition of mundane everyday activities, such as getting up out of a chair and walking down the hall without falling, help to give structure and a sense of meaning to a persons' life. For others, the availability of resources, including rehabilitation programmes, home care, and spiritual and religious

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resources are important for their ability to successfully engage in adaptation. Moreover, a sense of continuity is much more than the ability to carry out routines and activities. For some, a sense of continuity depends on the ongoing involvement with loved ones.

The fact that the level of disruption of stroke crosses so many different areas – physical, social and psychological – implies that the services/interventions necessary to provide holistic and timely care will need to embrace several disciplines. The literature points to lack of holistic care provided at point of discharge and lack of a sense of awareness of patients needs.

As one fundamental aim of rehabilitation is to support the social roles and maximise the sense of well-being of the person, rehabilitation practitioners need to address the wider concepts of life change, including physical, psychological and social changes.

The disruption that serious illness causes for people's lives draws attention to the fragility of a sense of continuity and the need for mechanisms and opportunities through which it may be recreated.

### **What does continuity of care mean to patients?**

None of the literature identified to date has specifically asked stroke patients what features of their own care created a sense of continuity, or what more could be done in this regard. A qualitative study of the views of patients and carers about the interface between primary and secondary care identified a set of themes which may be applicable (Preston *et al.*, 1999):

- 'getting in', i.e. successfully negotiating access to appropriate care;
- 'fitting in', concerning the establishment of satisfactory relationships with staff;
- 'knowing what's going on', reducing feelings of uncertainty and anxiety;
- 'continuity', i.e., receiving care from the same professional throughout the process or a sense of co-ordination and consistency between different providers;
- 'limbo', i.e. poor experience in any one of the four areas above, meaning there was a sense of not making progress and not being able to take any action to remedy this.

There are a number of studies which, having considered patients' experience of stroke care, suggest that similar problems arise in stroke. Two reports are particularly useful since they gather information across the continuum of care. One report focused on the development of an integrated stroke service in Walsall. Interviews were conducted with patients and carers to gather information to guide the development of the service, taking into account where the patients were; for example, in hospital, at Stroke Maintenance Centres or at home. The main themes which emerged from patients at home who had completed the whole stroke journey included the need for better communication, more 'formal' progress updates, more staff on the wards and more activities on both the ward and in the rehabilitation unit (Clinical Governance Support Team, 2004).

A second quantitative study, undertaken in the USA, reported that the process of stroke care, as measured by compliance with stroke guidelines, was

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associated with patient satisfaction (Reker *et al.*, 2002). The guidelines were developed to 'assist primary care providers and rehabilitation specialists in the care of patients with disabilities from stroke and to help patients and their families become better informed consumers of rehabilitation services'. Over a period of 2 years, patients were followed across the continuum of care, from acute inpatient to home, health, outpatient and nursing home care. The most important correlates of patient satisfaction were patient and family education, baseline assessments, discharge planning, family involvement and monitoring of patient progress. Not receiving enough therapy services, unhappiness with the amount of recovery, not enough community services, and insufficient information about expected recovery and about stroke prevention were associated with patient dissatisfaction.

Other studies evaluating the experience of stroke patients provide further insight into what would enhance a patient's sense of continuity of care. A review of qualitative studies was undertaken to identify the most frequently encountered longer-term problems experienced by stroke patients and their carers. The main finding of the review was the diversity and range of problems experienced by patients and carers, which cross the five themes identified above. A total of 203 problem areas were identified, which were categorised into five domains: hospital experience; transfer of care; services, communication; and social and emotional consequences (Murray *et al.*, 2003a). Patients reflected on negative hospital and discharge experiences. Difficulties with services included dissatisfaction with general practitioner (GP) contact, inappropriate goal setting, lack of longer-term contact and limited access to, or unawareness of, services. In a study evaluating the process of discharge from hospital in Southampton, insufficient therapy after discharge was a major source of dissatisfaction among patients, a view supported by GPs. Seventy percent of GPs felt that stroke patients did not receive enough therapy and that more physiotherapy, occupational therapy and speech and language therapy was needed. Sixty-seven percent called for greater emotional support and counselling for patients and carers (Tyson and Turner, 2000).

A postal survey of stroke patient and carer experience (Kelson and The College of Health, 2001) found that in terms of 'getting in' 16–24% of respondents who felt they needed physiotherapy, occupational therapy or speech therapy did not receive it. In terms of 'fitting in' 32% reported that they did not have access to staff with specialist knowledge of stroke. In terms of 'knowing what's going on', 22% said they did not receive information they needed, and in another 10% there was considerable delay in providing this. Patients and carers were also asked about the quality of care provided by their GP since their stroke, which arguably could be used as a marker of continuity. Seventy-four percent regarded this as average, good or excellent; 14% as poor or very poor; 4% had no contact with their GP. 'Limbo', an indication of problems in one of the other areas, may be implied from responses to a closed question about how quickly problems following the stroke were assessed. Seventeen percent stated that their problems had never been assessed, 7% that there was considerable unnecessary delay and 13% some unnecessary delay.

A number of studies specifically point to the importance of 'knowing what's going on' (see, for example, Tyson and Turner, 2000; Zwygart-Stauffacher *et*

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*al.*, 2000; Rodgers *et al.*, 2001; McBride *et al.*, 2004). Studies have repeatedly found that stroke patients and their families feel inadequately informed about all aspects of stroke disease and available support. Lack of information, leading to anxiety, misconceptions and fear, is believed to be a contributory factor to poor health status and emotional problems, both of which are common among stroke patients (Rodgers *et al.*, 2001). Stroke patients wish to be informed about all aspects of care and be involved in decisions but have difficulty obtaining the information they require: staff are perceived as too busy and often not available. Patients also feel reluctant to ask questions and the explanations given are often too complicated or do not address personal concerns. Despite the widespread evidence of the need to improve information-giving for stroke patients, relatively few evaluations of the content and method of delivery have been undertaken, and it is not apparent whether the available information addresses those issues which are important to patients. In stroke, as in other areas of healthcare, information is often based upon what health professionals think patients and carers want to know. The approach taken has predominantly been the passive provision of information rather than involving patients and carers in active learning and problem-solving.

There has been an increasing recent literature pointing to the dissatisfaction with GP contact, which arguably could be used as a marker of continuity. A consensus statement has suggested that the GP should arrange regular patient reassessments for those who have had a stroke, recognising at the very least that this would help overcome feelings of isolation and abandonment expressed by many patients and their carers (King's Fund Consensus Statement, 1983). In a systematic review of qualitative evidence to identify longer-term problems experienced by stroke patients, patients reported being unhappy with the quantity and quality of GP contacts. Two studies within the review reported on an expectation of home-monitoring visits which rarely occurred (Murray *et al.*, 2003b). In an ethnographic case series (Allen *et al.*, 2002a) a number of families expressed the view that their GP would assume a pivotal role in the care of the stroke patient, although this did not happen and for many GP involvement was minimal. In a trial designed to evaluate the effectiveness of specialist nurse visits to stroke patients and their families, qualitative data were collected on the patient's and carer's views of GP care following stroke. Thirty patients and their carers were interviewed in their own homes. It was clear that the role of the GP was considered important by patients and carers and there was a widely shared view that there should be regular contact with the GP following discharge from hospital. In general strong dissatisfaction was expressed at the lack of routine visits and the need to ask for help. Although all the patients interviewed had received services providing supportive care and home adaptations, only two patients and one carer identified their GP as facilitating the organisation of these services. For many, the main contact with their GP was for repeat drug prescriptions, and this was considered disappointing as it was less than the help they had hoped for.



### **Specific findings**

#### **The discharge process**

The point of discharge is one when stroke patients leave the familiar hospital environment with its structured care and have to rely on support from family, friends or other, unknown, carers. This is a self-evident critical point which the national stroke guidelines (Intercollegiate Working Party for Stroke, 2004) describe as an 'important watershed'. It is at the point of discharge that the need to manage the health and social care interface is at its most acute. This is a time when many of the clients' and carers' needs are uncertain and this uncertainty is often in tension with the requirement of health and social services to plan services. This can make it difficult to effect a timely and appropriate discharge. Yet, as mentioned above, strokes cause biographical disruption and the transfer from hospital to home is a time of great anxiety. Clients and their carers need time to adjust to their altered circumstances and make the necessary modifications to their family lives. This can conflict with the pressures to discharge patients that hospital and social services staff face (Allen *et al.*, 2002b). Part of the problem in managing the health and social service interface arises from the need to predict the future needs of patients in their home environment from the viewpoint of their current requirements in hospital. Alongside the prognostic uncertainty, it is unknown as to the effect of the clients' home environment on shaping their relative independence and the ability to cope (Allen *et al.*, 2002b).

Discharge planning is an important part of the continuity of care. There is evidence to suggest that if the discharge is well-planned and implemented, the patient is better prepared to cope with relocation (Naylor *et al.*, 1999). A systematic review has indicated that structured discharge planning with good documentation is thought to reduce readmissions and associated costs and improve patient satisfaction with care (Shepherd *et al.*, 2004).

There is evidence that discharge planning is often inadequate. The Southampton Stroke Project aimed to evaluate the quality of the process of discharge from hospital and follow-up services for people with stroke, by combining a detailed audit with surveys of patient satisfaction and staff opinion. In this area, there were no specialised stroke services. Stroke patients were admitted to either an acute medical ward or an older-people's care ward and rehabilitation was provided on acute wards, in a general elderly rehabilitation unit or in a rehabilitation unit for those under 65 years. After discharge, follow-up therapy was provided by day hospitals, outpatient neurological therapy or a generalist community physiotherapist. The project found a disappointingly low level of service with assessment, treatment and the provision of services all apparently geared to getting people out of hospital, rather than into rehabilitation, with an emphasis on discharging the patient with help, rather than enabling the patient to return to his or her former roles. There was evidence of poor communication between staff and patients, lack of co-ordination of procedures and a focus on discharge as an end in itself. Difficulties referring to social workers and liaising with social services were identified as a problem during the discharge process. Liaison with social services at the time of the home visit, prior to discharge, occurred in only 27% of cases, which meant that discharges were delayed or people

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were sent home without home care being arranged (Tyson and Turner, 2000). The College of Health survey (Kelson and The College of Health, 2001) reported that 40% of patients were not assessed by social services before leaving hospital, 48% did not receive a home care plan, and only 38% were given a name and number to contact if they needed help after leaving hospital.

In another study which examined the effectiveness of evidence-based discharge planning for stroke patients entering nursing home care, the information contained in hospital discharge letters from medical and nursing staff were examined. Results demonstrated that the completeness and accuracy of information was often poor, doing little to enhance the continuity of care for patients who were transferred from hospital to nursing home. The majority of discharge letters had no information regarding the patient's long-term care needs or social needs. Therapy staff often did not include any information about current or future treatment despite these patients requiring long-term rehabilitation, and the letters did not reflect the multi-disciplinary nature of stroke rehabilitation (Sackley and Pound, 2002a).

This same study set out to agree priorities for the structure and content of the discharge process for stroke patients entering nursing home care. A panel of 12 members of a multi-disciplinary team from a hospital and community setting used the nominal group technique to set priorities. Their opinion was combined with the evidence to create a list of items which were categorised into three distinct themes: the discharge process, patients' physical care needs and patient care needs. The priorities for discharge were:

- the discharge plan should be co-ordinated by a named person,
- a full assessment of needs for aids should be carried out and the findings given to the nursing home,
- patients should visit the nursing home before discharge,
- patient information should be recorded in written format,
- continuing rehabilitation plans should be included,
- staff at the nursing home should receive teaching on the patient's care before discharge,
- details of follow-up care should be included,
- hospital staff should carry out a follow-up visit to the nursing home,
- the patient should be given an outpatient appointment after discharge.

The qualitative data identified two emergent themes which affected choices in all three groups of rankings. These were 'use of resources' (efficiency) and 'how helpful is it' (efficacy). Throughout the discussions, the panel was concerned about the resource implications of the additional services that a new discharge plan could require. Overall, the panel group was found to be a practical and effective way of gaining agreement from practitioners from a variety of backgrounds with regard to recommending the information to be included in the written documentation and recommendations regarding the discharge process (Sackley and Pound, 2002b).

There are examples within the literature of patients' 'sense of abandonment after discharge' (Anderson, 1992) and evidence that patients are rarely involved in the discharge process. The Southampton Stroke Project, referred

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to above, found considerable dissatisfaction among patients about the services received during and after discharge, the amount of information, support and advice provided. Few people received any clear advice or education before discharge, discussed their future with staff or had access to therapists after discharge. Patients were also dissatisfied with the amount of service received once at home (Tyson and Turner, 2000). A case study described the phenomenon of power as it appeared in a discharge-planning conference, for an older woman who needed long-term care as a result of a stroke and heart failure. The content, structure and implementation of the planning conference was mainly controlled by the professionals, and influenced by a medical and organisational perspective. The patient experienced a feeling of powerlessness and of being treated as an object (Efraimsson *et al.*, 2003).

### **The role of carers and families**

The role of families and carers in ensuring continuity of care is critical. After initial hospitalisation and rehabilitation, an estimated 80% of stroke survivors return to the community, with more than a third dependent on an informal carer (Han and Haley, 1999; Smith *et al.*, 2004). Although additional formal support from community nursing services and allied health and social services may be provided, the onus of caring for patients at home usually falls on one or more informal care-givers who are often family members (usually spouses and children) and sometimes friends. The needs of the stroke survivor are often multiple and include help with physical activities, nursing activities, communication, psychological and emotional support and social reintegration into society (Hankey, 2004).

Recent changes in medicine and healthcare delivery have resulted in a shorter period of acute hospitalisation after stroke, and little time may be available between the sudden onset of stroke and discharge from hospital. Yet families are faced with multiple decisions and practical demands related to choice of care facilities, preparation of the home for discharge, and planning for care-giving, often with little preparation or knowledge of what to expect. In addition, the availability of home-based and community support is often limited. Families are being asked to do more, and to do it faster with less help than before (Palmer and Glass, 2003).

The consequences of care-giving can be numerous and cumulative. The altruistic benefits of contributing to the welfare of the stroke survivor and the community can be a rich source of motivation and carer satisfaction (Hankey, 2004), yet the burden of caring can cause serious disruption to carers' lives. Carers are often required to cope with a sudden change in mobility, communication, mood and personality (Han and Haley, 1999); in addition, they may need to learn new care-giving skills, take on additional responsibilities for household or financial management, spend more time at home providing supervision, and take over tasks for the stroke survivor. Families may have to modify their homes to accommodate wheelchair or other equipment. Families may also face economic stress. Sometimes it is necessary for a family member to give up paid work in order to provide personal care (Palmer and Glass, 2003). Care-givers are also required to redefine their self-concept and identity, adjust to alterations in communication and intimacy in their relationship with the stroke survivor, and cope with an

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erosion of leisure time and a lack of external recognition and support (Palmer and Glass, 2003; Hankey, 2004). In addition, carers themselves are likely to be older and have pre-existing illnesses or functional limitations (Smith *et al.*, 2004)

A qualitative study, which comprised semi-structured interviews with 90 carers to establish their experience of caring 1 year after the stroke, emphasised the above issues (Smith *et al.*, 2004). It found that carers' responses to stroke were individualised and depended in part on their own well-being and that of the patient, their previous social life, their family, their age, stroke severity and other life-changing events such as terminal illness. Following discharge, many carers found themselves at home and unprepared. Most interviewees were of an age where co-morbidity sometimes affected their ability to care. Some were aware of their own aging or deteriorating health and expressed concern about the future. They reported that they had not been asked if they could manage a house, cook, shop and assume financial responsibility. In fact, many lacked some or all of these skills. They felt their role as carer was taken for granted. Several carers found themselves having to deliver 'hands-on' care without any skills training. Very few carers reported GP follow-up despite the fact that most stroke survivors continued to feel medically vulnerable. In general, carers believed that the support required to lead their lives was not there – and if it was, it was extremely difficult to locate and mobilise. People were passed from person to person or department to department. Information was often found by chance. Carers felt abandoned and were disappointed by this lack of aftercare. Carers felt they had enough to cope with, without these additional burdens. For the few who accessed voluntary agencies, these proved to be important sources for information and equipment in the immediate post-discharge phase. Carers felt they needed some education about stroke, its effects and management prior to the patient's discharge from hospital, and to be included in and regarded as essential in the rehabilitation process.

In the College of Health Survey (Kelson and The College of Health, 2001), 60% of respondents stated that they needed help to live independently in their own homes; of these more than a quarter said their carer received no support, and 21% little support. Some 52% of carers reported problems getting support from the local health services and 49% the same for social services.

Evidence of distress faced by carers includes depression or low morale, anxiety burden, poor health and reduced family functioning. Worry, fatigue and the need to master multiple tasks related to the survivors' illness can contribute to distress during hospitalisation and the transition to home (King *et al.*, 2001). Previous research clearly demonstrates that care-givers are at elevated risk of depression, care-giver burn-out, social isolation and deterioration in physical health (Smith *et al.*, 2004). A systematic review of 20 studies of carers of stroke patients, mostly from the USA, showed consistently high rates of depression in carers, ranging from 34–52% (Han and Haley, 1999). A further review (Smith *et al.*, 2004) reported a study in which 55% of carers had clinically significant symptoms of depression, anxiety or other emotional disorder. There are reports of clinically significant care-giver depression as early as 1 month post stroke (Chumbler *et al.*, 2004).

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Overall, the literature suggests that two factors are strongly related to risk of psychiatric morbidity in stroke care-givers. First, the severity of the stroke and the resulting disability of the patient. Second, the presence of behavioural or emotional problems that alter the relationship between patient and care-giver and complicate the care-giving task. In addition, depression appears to be related to several other factors (Bugge *et al.*, 1999; Han and Haley, 1999; King *et al.*, 2001; Palmer and Glass, 2003; Chumbler *et al.*, 2004):

- decreased time for leisure and social activities, with consequent loss of social support for care-giver,
- the extent of actual care-giving demands,
- presence of depression or other emotional and behavioural problems in the stroke patient,
- in the cases of spouses or partners, changes in their sexual relationship with the stroke survivor,
- health status of the care-giver,
- nature of family functioning,
- there is some evidence that social support for family care-givers has a protective effect against depression.

Despite the potential for distress among care-givers, carer's needs do not seem to have received the attention they deserve. Separate assessment of carers' needs was only found in 36% of cases in the second round of the national sentinel audit (Rudd *et al.*, 2001a). There have also been few studies on their adaptation during the period when they initially assume care-giving, and major gaps are evident on the factors that may reduce or temper care-giver burden and depression. Instead, most studies of depression have focused on background and survivor illness factors, and not on social, environmental or coping variables. Such knowledge is needed, however, to develop interventions to ease the transition to role of carer. Early intervention for care-givers in terms of averting burden and depressive symptoms has important clinical implications for at least two reasons. First, early intervention can be effective for preventing later psychological and physical morbidity in care-givers. Secondly, effective interventions could improve the quality of life of the stroke survivor and reduce the need for long-term institutionalisation. There is evidence, for example, that care-giver burden and depression exacerbates the patients' depressive symptoms, predicts poor response to rehabilitation among stroke survivors and can lead to permanent entry into a nursing home (Chumbler *et al.*, 2004).

Research in this area has tended to focus solely on the patient-carer dyad. Palmer and Glass (2003) propose that the impact of stroke on carers needs to be considered from a family-systems perspective. This posits that the stroke survivor and family members are part of a complex integrated system with pre-existing patterns of relationships, norms, rules, communication styles and roles. As such, stroke poses a significant challenge to these relationship patterns around which the family system was organised and brings about a psychosocial transition that requires the reconstruction of family functioning. The process of stroke rehabilitation is not only about the recovery of mobility. It is a collaborative process in which rebuilding the foundations of identities, roles and relationships is equally important. A qualitative study emphasised

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how altered roles within relationships was a major issue among care-givers. For some this involved reversal of former domestic male/female roles; for others there was an assumption of additional responsibilities. For others there was a transformation of roles – most commonly that of husband and wife to patient and carer. In the presence of persistent cognitive and behavioural problems a few carers felt they were living with a stranger (Smith *et al.*, 2004).

From a family systems perspective, in so far as the family system is supportive, flexible, adaptive and high-functioning, it facilitates a successful psychosocial transition for the stroke survivor and ensures the continuity of meaningful family relationships. Family dysfunction, on the other hand, confounds and multiplies the difficulties involved in successfully resolving these core challenges. The impact of family function on stroke recovery has been most consistently investigated in terms of the family's role in providing social support for the stroke survivor, and a growing body of research demonstrates the importance of family relationships for the recovery of functional capacity in stroke (King *et al.*, 2001; Palmer and Glass, 2003). Measures of the qualitative aspects of support are almost completely lacking and therefore we know little about why certain behaviours are experienced as supportive or not within families. The literature review on family care-giving found that there is some evidence for the impact of family function on discharge disposition, treatment adherence, rehospitalisation, depressive symptoms and functional recovery. Aspects of family function that appear to be associated with these outcomes are (a) availability of a spouse or at least one close family member, (b) emotional support, empathy and affective involvement, (c) overprotection or overfunctioning of family care-givers, (d) family communication and (e) family problem-solving.

## ***Summary***

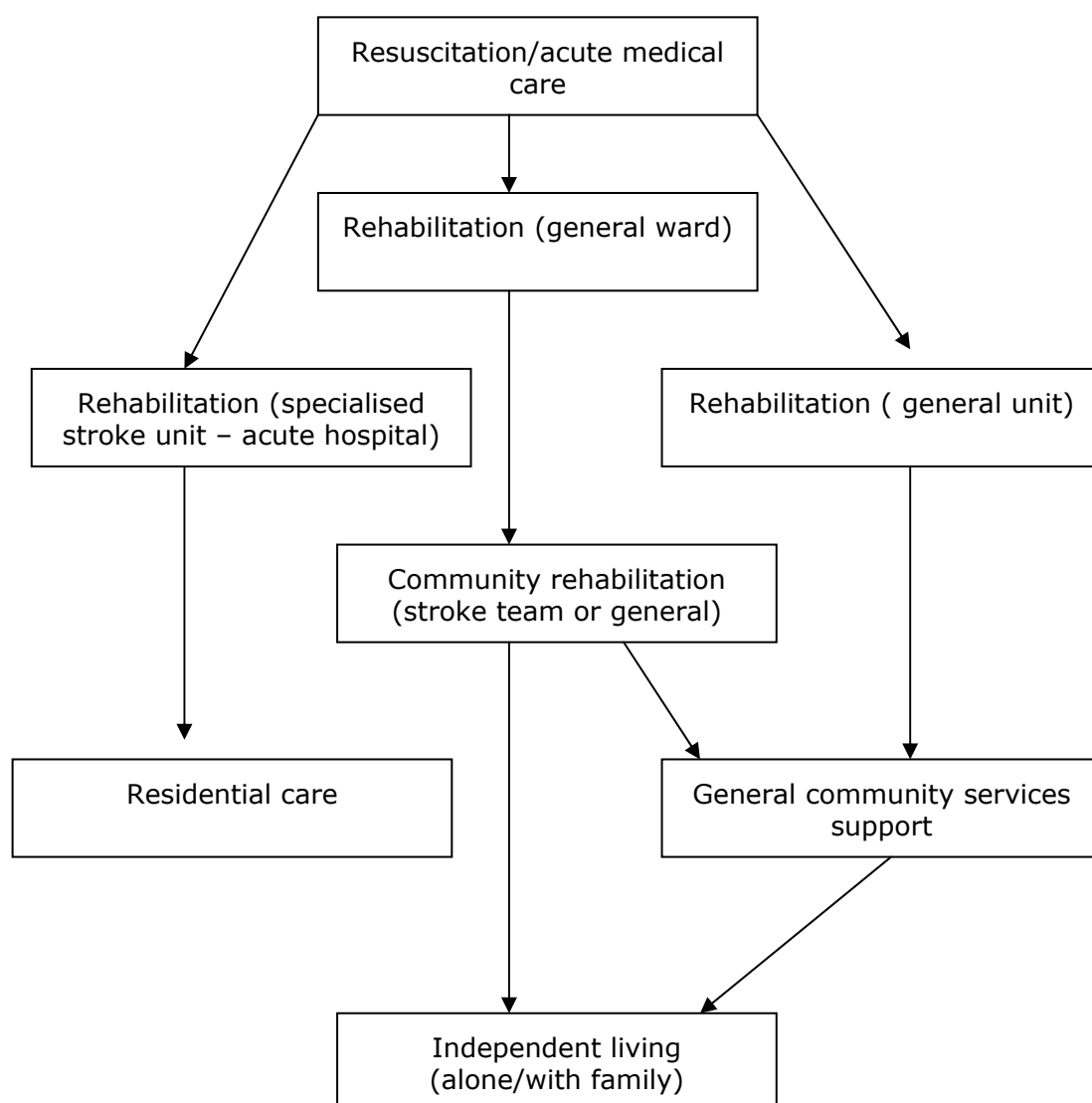
Figure A1 (overleaf) attempts to encapsulate the range of critical points (represented by arrows) which may be involved in the transition from acute care to recovery, on the basis of the literature.

## ***Reported innovations and service models***

Since publication of the Stroke Unit Trialists' report (Stroke Unit Trialists' Collaboration, 2002), a consensus has developed that stroke care delivered by specialised services is better than that delivered by generalists. More recent research has aimed to discover what particular elements of specialised services are responsible for this benefit, and how community services can further enhance this effect.

Most evaluations have used objective measures of survival and functional ability to demonstrate benefit rather than patient- and carer-orientated outcomes which are more directly relevant to continuity of care. In theory it is possible that improvements in 'hard' outcomes such as death and disability could occur without similar changes in more patient-orientated ones. Under these circumstances, incorrect conclusions could be drawn about the

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**Figure A1 The range of critical points that may be involved in the transition from acute care to recovery**

*Note: to avoid overcrowding the diagram, not all possible critical points have been shown.*

desirability of new types of care in terms of continuity of care. However, it seems unlikely that an innovation or new service model which worsened patient- and carer-orientated outcome could nevertheless reduce disability and prolong survival.

A wide range of innovations which may improve stroke outcome are described in the literature, ranging from specific pharmacological and physical therapy interventions, through to much more diffuse procedures such as extra staff training. Equally variable are the methods by which improvement in outcome is demonstrated; these range from the meta-analysis of randomised controlled trials, to small case series. An innovation or service model which has been positively evaluated by a 'rigorous' method such as a randomised trial is not necessarily more beneficial than one evaluated in a different way,

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so judgement will be required to identify which innovations are desirable in the current context.

The aim of this section is to list the innovations and service models which have been identified as possible ways to improve progress towards recovery or adjustment, and the strength of evidence which supports them.

Interventions to avoid the need for hospital admission or which only apply to patients who are not admitted are excluded, because our focus is on the partnerships and complexity of the transition to longer-term care. Similarly, interventions which relate to the organisation or delivery of a single professional service are also excluded.

### **Stroke units**

Organised inpatient (stroke unit) care is characterised by: (1) co-ordinated multi-disciplinary rehabilitation; (ii) staff with a specialist interest in stroke or rehabilitation; (iii) routine involvement of carers in the rehabilitation process and (iv) regular programmes of education and training (Stroke Unit Trialists' Collaboration, 2002). This general definition includes a variety of models which differ in the degree to which care is organised. The recent organisational audit (Royal College of Physicians, 2004) defined the following subcategories of stroke unit:

- acute stroke unit, which accepts patients acutely but discharges early (usually within 7 days); this could include an intensive model of care with continuous monitoring and high nurse staffing levels;
- rehabilitation stroke unit, which accepts patients after a delay of usually 7 days or more and focuses on rehabilitation;
- combined stroke unit (i.e. no separation between acute and rehabilitation beds), which accepts patients acutely but also provides rehabilitation for at least several weeks if necessary.

A recent systematic review of the literature published between January 1995 and July 2002 found six randomised controlled trials of stroke unit care compared with general medical ward care. Meta-analysis demonstrated that patients who had a stroke of moderate severity who receive care in a stroke unit were more likely to be alive and living at home after 10 years of follow-up. There was also evidence that patients who receive stroke unit care are more likely to undergo recovery, as assessed by the Barthel Index, compared with patients in the control group. There was no decrease in the length of hospital stay as a result of stroke unit care (Noorani *et al.* 2003). This review, therefore, confirmed the principal finding of the Stroke Unit Trialists' Collaboration within the Cochrane review, which at present contains information on almost 5000 patients from 23 clinical trials. This confirms that stroke patients who were managed in a stroke unit are less likely to die, require institutional care or have long-term dependency. Further corroboration of the benefits of stroke unit care has come from the National Stroke Register in Sweden (Gilbertson *et al.*, 2000). Whether patient-centred outcomes would mirror these differences in hard outcomes between stroke unit and conventional care is unknown, because they have been insufficiently recorded.

Despite these findings, there is still uncertainty about the relative effectiveness of specific models. The contribution of each component of the



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care package to the overall effectiveness is unknown, so that stroke unit care is often described as a black box. It has been hypothesised that stroke unit care provides superior care because of the specialisation of the interdisciplinary team, that they provide a greater intensity of stroke care, that they provide improved discharge planning, good communication and early involvement and good communication with patients, carers and relatives (Gibbon *et al.*, 2002; Noorani *et al.*, 2003).

The NSF for Older People set out that all hospitals caring for people with stroke should have a specialised stroke service by April 2004. An organisational audit (Royal College of Physicians, 2004) assessed how many of five key features, chosen as markers of stroke unit organisation, were in place within units claiming to be a stroke unit. The Department of Health national performance indicator on the proportion of patients admitted to a stroke unit uses a minimum of four of the five of these criteria to define a stroke unit. The five criteria are:

- a consultant physician with responsibility for stroke,
- formal links with patient and carer organisations,
- multi-disciplinary meetings at least weekly to plan patient care,
- provision of information to patients about stroke,
- continuing education programmes for staff.

The audit found that 82% of hospitals in England had a stroke unit, with 91% fulfilling four of the five criteria. The audit did, however, highlight variations in practice and staffing levels between units, and noted that clinical psychology services remained rare.

### **Early supported discharge**

Early supported discharge (ESD) involves the provision of stroke services through an organised rehabilitation team managing patients in their own communities, with the intention that stroke patients' length of stay in hospital can be reduced. The concept of ESD has arisen because it may be more acceptable to patients, inpatient multi-disciplinary stroke rehabilitation may not provide for optimal outcomes, given that the goal is to establish skills that are applicable to the home environment, and it may reduce the overall costs through a reduction in in-hospital stay. As with acute stroke units, the overall term includes a variety of models with important differences. A key distinction within ESD is between those services where the service is both planned and delivered by a specialist team and those where care is planned by the specialist team but provided by existing agencies.

Although there are fewer randomised controlled trials of ESD than stroke units a wider range of outcomes has been measured, including standardised measures of activities of daily living, subjective health status and carer satisfaction (Early Supported Discharge Trialists, 2002; Noorani *et al.*, 2003; Teng *et al.*, 2003). A recent systematic review reported on five randomised controlled trials of ESDs. In three trials, ESD was an extension of stroke unit care. Services were provided for up to 5 months. No reduction in the odds of death or institutionalised care for ESD patients compared with controls was observed at 6 month follow-up. No significant differences were observed between groups in the mean Barthel Index score, although a higher

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proportion of intervention patients were considered independent compared with controls in two trials. No differences between groups were observed in the proportion of patients at home at follow up or in health-related quality of life. The one significant finding was that ESD patients showed significant reductions in the length of hospital stay compared with controls. The range of length of hospital stay from randomisation to the ESD group was 2–18 days and 12–33 days in the control group, representing a 50% reduction in the ESD group. These findings resonate with the findings of two earlier reviews (Kwan and Sandercock, 2004), which found a significant impact on LOHS but no significant differences in outcomes of death, institutionalisation and dependency between those discharged early compared with conventional care groups.

Further trials have reported significant impact on LOHS (Bautz-Holter *et al.*, 2002; Teng *et al.*, 2003), and no significant differences between ESD and usual care in terms of functional outcome (Bautz-Holter *et al.*, 2002; Teng *et al.*, 2003; Askim *et al.*, 2004). At the same time there is no evidence that ESD increases care-giver burden. In one randomised controlled trial, care-givers experienced less burden and the greatest benefit for care-givers appeared to be for those who cared for persons with more severe functional limitations after stroke (Teng *et al.*, 2003). Other studies have shown no impact on care-giver burden (Askim *et al.*, 2004; Hackett *et al.*, 2002).

There is some limited evidence that ESD may enhance quality of life in patients. One randomised controlled trial evaluated a scheme for patients living in rural communities in Norway, which comprised of a mobile stroke team that offered ESD in close co-operation with the primary healthcare system during the first 4 weeks after discharge. Regarding quality of life there was a significant difference between the two groups for the domain social isolation at 6 months follow-up, favouring the extended service. The authors hypothesised that as the aim of the stroke team was to co-ordinate the primary healthcare system and to secure the needs of the patient and their family, this could have ensured less social isolation in the ESD group. The benefit may, however, be temporary since at 12 months the isolation of patients receiving conventional care had reduced. This finding is supported by another randomised controlled trial which found improved patient well-being in the intervention group 3 months post-stroke but not at 6 months post-stroke (Bautz-Holter *et al.*, 2002).

Overall, therefore, ESD trials suggest that stroke patients discharged early from an acute hospital setting can be successfully rehabilitated in the community by an interdisciplinary stroke rehabilitation team. These patients are able to attain similar functional outcomes when compared with patients continuing to receive 'conventional care'. It is worth noting, however, that the generalisability of the findings may be limited since many of the randomised controlled trials had strict inclusion criteria, admitting only those patients who had strokes of milder severity, where nursing care could reasonably be provided by the family at home. In addition, the nature of the interventions varied greatly and it is not clear whether particular elements are more likely to lead to more positive outcomes. Where ESD was not compared with another type of organised and co-ordinated programme, for example, it was hypothesised that it may have been the organisation and co-ordination itself

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that was responsible for the improved quality of life among those receiving the service (Teng *et al.*, 2003).

The organisational audit (2004) points out that as yet there are no definitions as to the constitution of an ideal ESD team, but that the research evidence suggests that medical, nursing and therapy input are all desirable. In the audit only 14% of hospitals in England have an ESD attached. One-hundred percent included an occupational therapist and a physiotherapist, 83% had a speech and language therapist, 38% had a social worker and only 8% had a psychologist. Only a third of teams had specialist medical input and only half had nursing involvement.

### **Integrated care pathways**

Integrated care pathways (ICPs) are a project network technique, which charts the order of activities and the nature of the relationship between different activities (Sulch *et al.*, 2002). They also anticipate outcomes of an episode of care (Patterson, 2002). It is a method of improving and co-ordinating interdisciplinary care without necessarily changing the clinical practice of individual disciplines, which has been used in a variety of areas in the NHS since the 1990s. The NSF stresses the key role of the ICP in the development of quality healthcare over the next 5–10 years (Sulch *et al.*, 2002).

Development of a care pathway requires the formation of a local multi-disciplinary team, and detailed discussion of the contribution of each discipline to the overall package of care. They are complex to establish and require considerable planning and staff training (Patterson, 2002; Sulch *et al.*, 2002). The potential of ICPs in improving stroke care and rehabilitation is open to debate. Advocates assert that they improve the co-ordination of care and provision of appropriate information, two critical points in the care process identified in the first section of the review. An effective stroke pathway could improve discharge planning and reduce the length of stay through liaison between disciplines and the provision of an organised, goal-defined template for rehabilitation. Others, however, argue that ICPs are overly prescriptive and inflexible and that they militate against individualised patient care (Patterson, 2002; Sulch *et al.*, 2002).

Published evaluations of ICPs for stroke care have shown mixed results. A Cochrane systematic review, comparing ICPs in acute care with standard medical care, located three randomised controlled trials and seven non-randomised studies. A care pathway was defined as a plan of care that involved two or more disciplines and involved two or more of the following aspects of care: assessment, investigation, diagnosis and treatment. The review highlighted the variable definition of a care pathway. No two studies had used the term care pathway to describe the same type of intervention. Their care pathways seem to have differed in terms of their components, target patient groups, location of use and methods of design and implementation (Kwan and Sandercock, 2004).

The review concluded that there was no evidence that ICPs provided additional benefit over standard medical care in terms of major clinical outcomes of death, dependency or discharge to home. Data from the non-randomised studies provided weak evidence that ICPs improved the

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process of care, resulting in fewer complications and more thorough investigations. The authors also concluded that ICPs might be associated with adverse effects on patient satisfaction and quality of life (Kwan and Sandercock, 2004). The authors believed that there was insufficient evidence to justify routine implementation of care pathways for acute stroke care management or stroke rehabilitation.

The data from one of the randomised controlled trials, included within the review which found no significant difference between ICP care and conventional stroke unit multi-disciplinary care in terms of mortality, institutionalisation, functional recovery and length of stay, was revisited more recently to assess whether the ICP improved other outcomes, namely quality of life, patient/carer satisfaction and the processes of care (Sulch *et al.*, 2002). The authors found that ICP-led stroke rehabilitation was associated with poorer quality of life than conventional care and there were no significant differences in patient and care-giver satisfaction between the two settings. They concluded that better quality of life in patients receiving conventional multi-disciplinary care may have been attributable to the improved social functioning this group of patients achieved, and greater attention to supporting care-giver needs during rehabilitation (Sulch *et al.*, 2002; carer one).

The authors of this study also considered that the outcome measures previously studied might have been insensitive to improvements in the process of care resulting from the implementation of the ICP. They utilised the InterCollegiate Stroke Audit Tool developed by the Royal College of Physicians' Clinical Effectiveness and Evaluation Unit to measure the process of care in the domains of assessment, rehabilitation management, secondary prevention, discharge planning and communication. Review of the ICP records showed good compliance with the care pathway in all the domains assessed. The primary outcome (the proportion of patients receiving recommended interventions) was favourable in the domains of assessment, rehabilitation management, secondary prevention, discharge planning and communication, although the time taken to implement the intervention varied considerably from patient to patient. There were, however, no significant differences in the process of multi-disciplinary care, interdisciplinary co-ordination, patient management or discharge planning between the two groups (Sulch *et al.*, 2002).

The authors of this study have, therefore, looked across a wide range of outcomes. The results suggest that a stroke ICP may lead to some better care processes. However, no differences in clinical outcomes, patient and carer satisfaction were found. There was, in addition, some evidence that ICP care resulted in a lower quality of life for patients than did conventional multi-disciplinary care. Suggested explanations for this lack of effect were that the specialist team were already well co-ordinated so that ICP could add little; stroke patients show considerable variability whereas ICPs assume a predictable pattern of recovery and may lack flexibility required to adjust for variations and complexities of stroke rehabilitation; and of particular relevance to the present study:

*...dependence on external influences such as accommodation, personal support and services provided by other organisations that may not share the priorities of the treating unit.*

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(Sulch *et al.*, 2000)

A recent non-randomised study, which evaluated whether the use of ICPs and team notes improved team working on a variety of different stroke units, also found that external factors over which the multi-disciplinary teams had no control appeared to have been more important in the process of care than the introduction of the team care interventions (Gibbon *et al.*, 2002). The study found that the introduction of ICPs had no impact on team working in established stroke units. Staff attitudes were found to be largely ambivalent and not significantly affected.

The studies have, therefore, indicated that ICPs have little benefit in stroke care and rehabilitation. ICP-led management may lack the flexibility required to adjust for variations and complexities that will necessarily arise in stroke rehabilitation. It is, however, noteworthy that the ICPs have been introduced and evaluated, in the main, in established multi-disciplinary stroke units, where their potential to enhance the process of care is limited. It may be that in areas of healthcare with poorly organised, haphazard, fragmented services and wide variations in practice, ICPs may have greater impact (Patterson, 2002).

### **Family interventions**

It is clear from the previous section that carers are a vital resource in the process of care and rehabilitation for stroke patients, that they are under great strain and that there is increasing evidence on the impact of caring on the well-being of carers, the wider family, and the stroke patient themselves. A service designed to support informal care-givers and enhance their quality of life is, therefore, likely to have a direct impact on patients' quality of life, and emotional and physical health. In this review the term family interventions is used to describe those specifically targeted at the main care-giver and/or the family. These include stroke liaison workers, stroke education packages and training carers in basic nursing and personal care techniques. The evidence around their existence and impact is, however, limited.

A review of interventions after stroke identified only 10 studies between 1982 and 1997 that included the family (Palmer and Glass, 2003). Of these, only one included counselling; the others were limited to education or group-support systems.

### **Stroke liaison**

A stroke liaison worker can be defined as someone who provides emotional and social support, provides information to patients and their families and liaises with services with the aim of reducing handicap and improving quality of life for patients and carers. A variety of different types of worker have been evaluated, such as nurses (Forster and Young, 1996; Boter *et al.*, 2004), family care workers (Dennis *et al.*, 1997), and family support organisers (Lincoln *et al.*, 2003).

Evaluation of such interventions by randomised trials have not shown uniform benefits. One of the difficulties is that these evaluations have tended to be co-located with well-organised stroke units and follow-up is generally limited. Benefits may be greater in other settings and over a longer time period.

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Evaluation of specialist nurses resulted in some improvement in activities of daily living for mildly disabled patients (Forster and Young, 1996), and in another study family workers resulted in a reduction in carer depression (Dennis *et al.*, 1997).

More recently there have been evaluations of the Stroke Association's Family Support Service (Lincoln *et al.*, 2003). This is a needs-led emotional support and practical information service. The family support organisers play an active and invaluable role within the acute and community-based multi-disciplinary stroke teams. The family support organiser makes initial contact with the patient in hospital, attends case conferences and liaises with the rehabilitation team regarding discharge. The family support organiser helps families and carers prepare for the changes that they will have to make and supports them through the early days of adjustment. After discharge the family support organiser visits patients and care-givers at home to discuss problems, offer information and emotional support and direct them to appropriate services. Family support organisers establish and maintain regular contact with their clients, including monthly phone calls and follow-up visits.

The quantitative evidence, based on a randomised controlled trial, found no significant impact of the service at 9 months on patient outcomes (Lincoln *et al.*, 2003). At 9-month follow-up there was no impact on care-giver mood, strain or independence. The service did, however, result in increased knowledge for carers' about stroke, and carers were more satisfied with stroke information (Lincoln *et al.*, 2003).

In addition to these quantitative findings, there has been some qualitative investigation of the perceptions of family support organisers. There has been concern that many of the measures used in trials of the service attempt to assess mood and emotional adjustment. An observation study, however, of family support organisers reported that emotional support seems to be a minor role for family support organisers, and that they primarily engage in practical support and information provision (Harding and Lincoln, 2000). It is argued that quantitative analysis of family support organisers has failed to uncover the overall effects of the complex and multifaceted role, and that some of the concerns raised in interviews with stroke patients and their carers would not have fitted into existing classifications of routine outcome assessments (Pound *et al.*, 1998a).

The authors of one of the randomised controlled trials referred to above (Lincoln *et al.*, 2003) also conducted semi-structured interviews with 20 patients and carers to ascertain their perceptions of the family support organiser service. Interviewees who received the service reported that the presence of the family support organiser was valuable in many respects including as a source of information on stroke, providing continuity between stroke services and providing help to claim benefits. The family support organiser also allayed many concerns of not knowing what to expect after discharge from hospital, and many felt relief at having someone acting on their behalf when dealing with other professional services, because they often felt overwhelmed with how complex things were. Emotional support was only described by a few. Interviewees who did not receive the service reported feelings of isolation and being let down by other stroke services following discharge from hospital. They also reported problems accessing information. The importance of dealing with practical problems after stroke was highlighted

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mainly in the control group interviews. Reference was made to difficulties encountered trying to obtain practical equipment in the home to assist with activities of daily living. The difficulties appeared to lie in feelings of 'being fobbed off' by those who should provide this assistance. In addition, there was frustration and stress created by the need to search for information and support. The time at which most support from the family support organiser was needed came across in the majority of the interviews. There appeared to have been many anxieties on discharge (Lincoln *et al.*, 2003).

Overall, information provision and indirect support seem to have been two of the most valued aspects of the family support organiser service. The authors concluded, however, that provision of appropriate and effective emotional support may be outside of the family support organiser's remit. Furthermore, the authors argue that the findings support the argument that efforts to improve the quality of life for patients and carers do not necessarily lie in the provision of counselling or other specific forms of support. The findings suggest that the subtle mechanisms through which support is offered is what is valued. An understanding of these processes will help deliver more effective and appropriate interventions (Lincoln *et al.*, 2003).

Other evidence indicates the value placed on stroke liaison workers. A qualitative study on the experiences of carers found that carers found staff in hospital, including therapists and doctors, to be too busy. This made them difficult to approach. Carers preferred staff with an open, friendly manner who approached them, such as a stroke liaison nurse who sought out a carer, answered questions and provided a contact number. In this study carers wanted more prolonged contact with a stroke liaison nurse but the caseload was often too large to provide the extended service (Smith *et al.*, 2004).

### **Stroke education**

Little is known about the effectiveness of specific stroke education packages, despite some degree of stroke education being available in many rehabilitation programs. Overall the evidence is mixed. The interventions have the most beneficial impact on the amount of, and satisfaction with, knowledge about stroke that carers receive. There is, however, limited evidence of any beneficial impact on patient and carer outcomes. It appears that education interventions need to be coupled with other family interventions, such as counselling, before any significant impacts on patient and carer outcomes are witnessed.

In one of the few randomised controlled trials of stroke education, a 7-hour stroke-education program was provided to stroke patients and their care-givers (Rogers *et al.*, 1999). This begun during hospitalisation and continued on an outpatient basis. Education was provided by rehabilitation professionals and included sessions on the experience of stroke, treatment and recovery, physical and occupational therapy for stroke, the psychological effects of stroke, care-giving, communication and swallowing problems and reducing stroke risk. Patients in the control group were given leaflets from the Stroke Association and prior to hospital discharge were given the phone number of a stroke hotline run by the hospital. Patients and care-givers who received the stroke-education program demonstrated increased knowledge about stroke and greater satisfaction with the information they received.

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However, there was no difference between the two groups on perceived health status, emotional status or functional ability.

A further controlled study evaluated the outcomes of two types of support programmes for care-givers which aimed to improve care-givers' active coping, knowledge of stroke and well-being (Van Heuvel *et al.*, 2002). The interventions were based on three elements: expressing emotions, receiving information and learning how to use active coping strategies. One intervention consisted of an 8-week group programme, providing 16 hours of education. The other was an 8–10-week home visit programme where care-givers received 8 hours of education. After 6 months, the interventions contributed to a small to medium increase in knowledge and use of an active coping strategy. The amount of social support remained stable in the intervention groups, whereas it fell in the control group. There were no significant differences between the two interventions. The interventions had no effect on care-givers' physical or mental well-being. The authors speculated that, since these interventions were offered between 6 months and 3 years post-stroke, the effects may have been greater if offered immediately following the stroke.

A randomised controlled trial, conducted in Australia, evaluated the impact of an education programme combined with counselling on family functioning and functional and psychosocial outcomes for stroke patients and their carers. Patients and carers in the intervention group received a stroke information package at discharge providing general information about stroke and its consequences, highlighting measures for the reduction of risk of further stroke, providing practical suggestions for coping and giving information about community services and support structures. In addition, there were three visits from a social worker trained in family counselling. After 6 months, the intervention group had better family functioning than the group who did not receive the package of care. The authors concluded that an education and counselling intervention maintained family functioning, and in turn improved functioning and social patient outcomes, although there were no significant effects on depression, mastery or anxiety (Clark *et al.*, 2003).

A review of family interventions reported that although there were few studies stroke education programs appeared to be clearly valued by patients and care-givers and resulted in improved stroke knowledge. There was some evidence, however, that education needed to be coupled with other interventions, such as counselling, to achieve 'objective' gains in patient and carer outcomes. The authors of the review concluded that further research was needed to determine the value of stroke education programs (Palmer and Glass, 2003).

### ***Training carers in basic nursing and personal care techniques***

There is some evidence that training carers in basic nursing and personal care techniques, such as moving and handling, facilitation of activities of daily living, management of pressure areas and prevention of bed sores and continence reduces care-giving burden, anxiety or depression and improves patients' and carers' quality of life (Kalra *et al.*, 2004; Patel *et al.*, 2004). In a randomised controlled trial carers were trained within a Stroke Rehabilitation Unit, once patients' needs had stabilised and discharge was contemplated, and the outcomes were compared with those who had received no training.



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Carers received three to five sessions of training in the unit, and a follow-through session once the stroke survivor was at home. Although patients' mortality, rate of institutionalisation and disability were not influenced by care-giver training, the authors concluded that a higher proportion of disabled stroke survivors achieved independence at an earlier stage, the mood and quality of life of disabled stroke survivors and care-givers were improved, and the cost of stroke care was reduced (Kalra *et al.*, 2004; Patel *et al.*, 2004). The cost advantages seem to be a result of earlier discharge from hospital in the training group. The most likely reason is that training and some input into care before discharge may have increased the confidence and competence of care-givers who were then more capable of continuing rehabilitation process at home.

Overall, therefore, there is evidence that family interventions provide benefits to both patients and carers. Whereas the quantitative evidence is limited, qualitative studies, in particular, have highlighted the value of approachable stroke liaison workers who have provided continuity between services and valuable information. Valued and beneficial aspects of these different types of interventions appear to be the provision of information, practical training and continuity of service. A study that aimed to construct a questionnaire to measure the satisfaction of informal carers of stroke patients in the community with community services confirms these findings (Simon *et al.*, 2002). Factor analysis revealed seven factors that were associated with satisfaction:

- information about community support and involving the carer,
- amount, appropriateness and co-ordination of services,
- information about stroke,
- speed of change and concern about the carer,
- listening to the carer and being heard,
- problem management,
- confidence in and accuracy of information.

The implications of these findings is that the rehabilitation and care of stroke patients should be broadened to include the proposed care-giver involving them actively in setting goals, rehabilitation, care and planning discharge and ensuring that they are adequately trained, supported and followed as the patient (Hankey, 2004; Legg and Langhorne, 2004).

### **Other models of stroke care**

Effective longer-term management of patients after discharge from hospital is critical as patients can continue to benefit from rehabilitation and help with reintegration for a prolonged period after stroke. The objective should be to transfer the care of patients from hospital to community and not to discharge (Royal College of Physicians, 2004). The audit found that 25% of hospitals have a specialist stroke community team in areas for continuing longer-term management. There is evidence around the impact of community services providing co-ordinated multi-professional treatment to stroke patients. The difficulty is that the interventions differ widely in terms of their composition, their timing and duration and their target populations, thus making evaluation of the evidence problematic. A recent systematic review appraised eight

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randomised controlled trials which evaluated home-based rehabilitation services provided by an interdisciplinary team of professionals including physicians, nurses, occupational therapists and physiotherapists compared with patients receiving routine rehabilitation services in either a hospital or community setting. No significant inter-group differences were observed for death, dependency, health-related quality of life or rates of institutional care. Patients in the home-based intervention group showed reductions in hospital readmission rates compared with controls (Noorani *et al.*, 2003). Another systematic review of a group of 14 heterogeneous trials found that therapy-based rehabilitation services, provided by multi-disciplinary teams, for stroke patients living at home reduced the odds of deteriorating in personal activities of daily living and increased the ability of patients to do these personal activities. The exact nature and content of therapy-based rehabilitation services was not answered by this review; neither was the most effective way to structure provision of these services (Outpatient Service Trialists, 2004).

There is some evidence that interdisciplinary community teams can result in benefits for patients and carers. In a randomised controlled trial Lincoln *et al.* (2004) found that patients treated by the Community Stroke Team were more satisfied with the emotional support they had received than patients receiving usual care, and had equivalent outcomes in terms of independence, activities of daily living and mood. Their carers were under less strain and were more satisfied with their knowledge of stroke recovery, the emotional support they received and overall satisfaction with the services.

A further randomised controlled trial evaluated an interdisciplinary post-discharge care-management scheme which provided care with an equal emphasis on physical and psychosocial health. The intervention included an advanced practice nurse manager to assess patients problems and co-ordinate care and used a team of stroke experts to devise individual care plans. The model resulted in a significantly better profile of health and secondary prevention when compared to post-discharge care 3 months post-discharge (Allen *et al.*, 2002b).

### **Patient-held records**

A controlled trial evaluated whether the use of a patient-held record (PHR) would result in greater patient satisfaction and better care planning for stroke patients. It was hypothesised that the PHR might bridge the gap between hospital and the community, contributing to continuity of care. The PHR was a booklet held by the patients containing the telephone numbers of all relevant staff. Space was provided for assessment and management decisions to be recorded, and patients could also record their own comments. Intervention group patients were more satisfied with the recovery they had made, but felt less able to talk to staff about their problems. They reported receiving fewer explanations about their condition and treatment and were more afraid of asking doctors questions than control patients. PHR group patients were no more prepared for discharge than the control group patients and both groups were ill-informed about services and benefits that might have helped after discharge. A PHR didn't improve patient satisfaction or discharge planning, and it may have reduced opportunities for communication and explanations (Ayana *et al.*, 2001).

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### **Nurse care managers**

A recent study illustrates the variety and range of interventions performed by a nurse care manager to community-dwelling stroke survivors and their families following discharge from an acute-care facility. The multiple and diverse effects of stroke and the complexity of the healthcare system required the nurses to use a variety of interventions aimed at successful reintegration into the community. The intervention was designed to bridge the gap following hospital discharge. The stroke survivor was contacted within 24 hours of discharge and had at least weekly contact with the nurse for 6 weeks. Interventions were individualised to meet survivors specific post-discharge needs, with a focus on linking the stroke survivor with community services. There was evidence that the intervention was bridging the gap between hospital and home, as nearly a quarter of all interventions provided focused on supporting effective use of the healthcare system. This involved co-ordinating care across settings, facilitating access to health services, facilitating the flow of information between hospital and GP, and identifying agencies that offered the care needed by stroke survivors. Patients and their families were helped to navigate the healthcare system, including informing them about the roles of different healthcare professionals and the services they offered. Other interventions included behavioural, which focused on supporting psychosocial functioning and facilitating lifestyle changes, including nutritional counselling, smoking-cessation assistance and family support interventions. Families were included in teaching about stroke, medications and lifestyle modification and symptom management.

Active listening, where nurses actively encouraged participants to express their feelings, was used by about a third of stroke survivors and their family members. Situations where this intervention was used included stroke survivors talking about losses related to the stroke or family members talking about adjustments that the family and stroke survivor were making. Also used during discussions where stroke survivors and families expressed their frustration at the difficulties in accessing healthcare resources (McBride *et al.*, 2004).

*Multi-disciplinary workshops* (Rudd *et al.*, 2001a): a series of 17 workshops were held after the first round of the national sentinel audit, each attended by 50–100 clinicians. Breakout groups were held to discuss key issues in changing practice. There was no formal evaluation of the effectiveness of these events in stimulating change, although they were perceived as useful and have been repeated since.

*Domiciliary occupational therapist* (Gilbertson *et al.*, 2000): a 6-week course with a domiciliary occupational therapist in addition to day hospital follow-up, when indicated, produced a significant reduction in the number of patients with a poor global outcome at 8 weeks (24 versus 49% in the control group). This differed for ESD in that there was no intention to reduce the initial hospital length of stay.

### **Summary**

The main function of this structured review of the literature on continuity of care in stroke services was to provide a solid basis for the conduct of the

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empirical research reported in the main text. Overall, the literature tends to focus on specific points in the trajectory of the person who has a stroke, and as a result one is left to piece together the evidence about the total experience of treatment, diagnosis and care. There is clearly substantial evidence about the fragmentation of services, due to both inter-organisational and inter-professional factors. Our understanding of continuity of care, especially as seen along the whole of the trajectory taken by individuals who have strokes, is not well developed.

### **Appendix 1 references**

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## Appendix 2 Research instruments

### ***Stroke topic guide: interviews with patients (and their carers)***

- 1 Circumstances of recent stroke: when, where and nature of onset?
- 2 Events from time of stroke until arrival at hospital  
which service(s) alerted and by whom  
approx time taken
- 3 Events from time of arrival until admission to stroke ward (acute/rehab):  
or other ward if no stroke ward.  
where moved: ward (hospitals)  
seen by which specialists  
approx time/duration
- 4 Any previous strokes (or TIAs)?  
where and when  
place, duration and nature of treatment/rehab/care
- 5 Any recollection – whether before or after arrival at hospital of:  
delay/disruption/disjointedness  
things being repeated apparently unnecessarily  
questions unanswered
- 6 Views about information and communication (how much, how and when informed) re:
  - a Stroke: the condition  
what has happened – in terms of the stroke – and why?  
what are the likely consequences?  
what is the proposed treatment, rehab and care?  
stroke in general: causes and preventive measures?
  - b Planning the treatment/rehab/care  
goals (short and long term)  
care plan  
discharge plan
  - c Ward policies and protocols
  - d Other: including complaints procedures and voluntary organisations (users and carers)
- 7 Views about involvement in planning processes: goal setting and care/discharge planning.
- 8 Describe a typical day on the ward:  
seen by: doctors, nurses, therapists, others  
activities: what, where, duration.

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- 9 Views about how treatment/rehab/care is given.  
PROMPT: organisation/co-ordination  
delay/disjointedness  
nature/quality of caring relationships
- 10 Views about the ward and hospital:  
the physical environment  
food  
routines, rules, procedures
- 11 Discharge planning process:
  - a who involved?  
patients and family/carers  
hospital staff (doctors, nurses, therapists etc)  
other NHS staff (e.g. community therapists)  
local-authority staff (social services, housing)  
other
  - b what involved?  
environmental visit  
home visit (part-day; overnight or weekend)  
case conference  
other meetings
- 12 Views about level of involvement (patient and family/carer) in discharge planning:  
what was assessed?  
what was proposed/arranged  
what degree of 'negotiated agreement'.
- 13 The process of discharge: date/timing:  
was it as planned?  
if not: why the change/delay?  
views of the delay
- 14 The process of discharge:  
availability of:  
equipment  
medication  
contact details  
information on:  
what will happen next  
outpatient appointments  
home visits  
day care  
secondary prevention  
treatment/rehab/care plan (including review arrangements)
- 15 The process of discharge: patient and family/carer perceptions of:

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the process

the notion of 'discharge'

- 16 Are post-discharge services as planned?

If not: explanation given

perceived effects

what provided instead

- 17 What would patients and families/carers like to see changed/improved – and why:

in services currently received?

services not currently available?

- 18 What from their experience, are the most important factors in (a) promoting and (b) inhibiting continuity of care?

**SDO continuity of care study: stroke**

**General locality audit and interview schedule for service professionals and managers**

(To be tailored as appropriate.)

**Preamble**

- Study background
- Current phase of fieldwork
- Reporting arrangements
- Confidentiality/anonymity

**I Organisation of care**

**1 Specialist stroke services**

Do you have a geographically distinct Specialist Stroke Unit?

No. of beds

acute:

rehab:

combined:

- If yes- when established?
- If no, what plans- given NSF milestone of April 2004?

Do you have a neurovascular clinic for the rapid assessment of TIA and minor stroke?

- If yes- where located?  
by whom staffed?
- If no- what plans?

Do you have a Specialist Stroke Consultant?

- If yes- when appointed?
- If no- what attempts to recruit?  
what plans to recruit?  
who is nominated Lead Clinician?

Do you have a Specialist Community Stroke Team?

- If yes- composition (WTEs)?  
when established?  
formal links with hospital specialist stroke unit?
- If no- what community support?

Do you have a co-ordinated, integrated multi-disciplinary Stroke Team?

- If yes- composition?

WTEs

Sessions

## ***Partnership and Complexity in Continuity of Care***

- specialist nurses
- specialist physios
- specialist OTs
- SALT
- dietician
- clinical psychologist
- social worker

Are there sufficient key professionals?

Are there sufficient sessions/hours?

If there are insufficiencies, what is being done:

reconfiguration of workloads?

training of all staff?

recruitment/retention policies?

Do you have a stroke co-ordinator?

- If yes- are they part of the MDT or additional?

Is it an explicit part of the stroke co-ordinator's remit to ensure continuity of care?

## **2 Interdisciplinary team working**

Are you operating a single assessment process (SAP)?

- If no- when is planned introduction?

Do you have locally agreed protocols used by the whole MDT? [obtain copy]

- If no- when is planned introduction?

Do you have multi-disciplinary patient records? [obtain blank copy]

- If no- when is planned introduction?

Do you have agreed protocols for common problems?

- If no- when is planned introduction?

Do you have an agreed Stroke Care Pathway? [obtain copy]

- If no- when is planned introduction

Are there weekly meetings of the Stroke Team?

- If yes: purpose/remit?

core attendance?

medical?

nursing?

therapy?

others' attendance?

dietician?

clinical psychologist?

social worker

## ***Partnership and Complexity in Continuity of Care***

### **3 Information, communication and involvement**

Do staff have access to information on:

- functional assessment/measurement tools
- practice guidelines
- patient/carer support organisations
- patient management in acute care

Please describe the discussion with/involvement of patients and carers re:

- diagnosis/prognosis
- therapy goals

How are patients and carers genuinely involved in planning their care, therapy and safe discharge?

Are carers' needs separately assessed?

Are carers taught skills to care for patients at home?

Do patients have access to information about their:

- diagnosis
- prognosis and assessment of need
- treatment and care plans

Do patients have access to information on the unit/ward re:

- stroke (condition and services)
- national/local guidelines
- social services
- Benefits Agency
- voluntary organisations
- complaints procedures

Does the stroke service have formal links with both patient and carer organisations?

- If yes, please describe
- If no, what informal links?

Is there a community user group for stroke?

## **II Clinical audit**

### **1 Casemix**

What % of all stroke patients:

- (a) are admitted to a specialist stroke unit?
- (b) have the majority of their stay in a specialist stroke unit?

What is the length of stay in the specialist stroke unit:

- (a) mean?
- (b) range?

What % of all stroke patients during their hospital stay are in;

## ***Partnership and Complexity in Continuity of Care***

- (a) 1–2 wards
- (b) 3–4 wards
- (c) 5+ wards
- (d) more than one hospital?

### **2 Multi-disciplinary assessment**

What is the level of compliance with the 6 Sentinel Audit standards?

within 7 days of stroke the patient became responsibility of a recognised multidisciplinary team of clinicians specialised in stroke;

swallowing assessed by Speech and Language Therapist within 72 hours of admission;

patient assessed by Physiotherapist within 72 hours of admission;

initial assessment of communication problems by speech and language therapist within 7 days of admission;

patient assessed by Occupational Therapist within 7 days of admission;

social work assessment within 7 days of referral.

If standards not yet met: why and what plans to achieve them?

### **3 Screening and functional assessment**

What is the level of compliance with the 5 Sentinel Audit standards?

patient weighed at least once during admission;

assessment of nutritional needs documented;

pre-stroke function recorded (e.g. Barthel Score);

function at discharge recorded (e.g. Barthel Score);

evidence patient's mood has been assessed.

If standards not yet met: why and what plans to achieve them?

In particular, how important is lack of mood assessment? And does this reflect insufficient clinical psychology input?

### **4 Management/care planning**

What is the level of compliance with the 5 Sentinel Audit standards?

written evidence that rehabilitation goals agreed by multi-disciplinary team;

individualised goals include reference to areas of higher level functioning;

plan to promote urinary continence?

is there evidence of a plan to prevent post-stroke complications:

(i) positioning and handling?

(ii) prevention of deep-vein thrombosis?

If standards not yet met: why and what plans to achieve them?

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### **5 Primary/secondary interface: discharge planning**

What is the level of compliance with the 3 Sentinel Audit standards?

home visit performed;

GP informed of patients discharge/death by day of discharge/death;

discharge summary to GP includes functional ability at discharge;

If standards not yet met: why and what plans to achieve them?

### **6 Continuity of care around discharge: other interfaces**

In addition to these latter standards, what needs to be in place to ensure continuity of care around the patient's discharge from hospital?

PROMPT

- prior involvement in discharge planning of:
  - local-authority social services
  - housing (local authority/other)
  - user/carer organisations
  - other voluntary organisations
- communication with these organisations

How well organised and how effective is such involvement and communication locally?

- principal successes?
- principal shortcomings?

How are the shortcomings being addressed?

### **Strategic service planning/organisation and management**

Is there an inter-agency strategic planning forum/group for stroke services?

- If yes:
  - remit?
  - composition?
  - frequency of meetings?
  - outputs?
- If no: where does strategic planning take place?

In line with the national guidelines, do you have local guidelines – agreed between commissioners and providers – on the following:

which providers are involved in providing co-ordinated, specialist stroke services?

in the absence of a specialist Stroke Consultant, who is the Lead Clinician?

the responsibilities of each provider?

who will undertake a local needs assessment?

in the current absence of a specialist stroke unit, where it will be sited and when it will be built?

what is the appropriate balance of services: hospital, day, domiciliary?



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collaboration/integration/partnership arrangements?

how (by whom) training will be provided?

how many specialist staff are required?

Please describe the local planning arrangements

requirements (timetable, format etc)

links between various plans

- what input to PCTs Local Delivery Plans (LDPs)
- what input to other local planning mechanisms
- what are the LDP milestones for stroke services?  
are they quarterly or monthly? (i.e. are they regarded as 'critical deliverables' or not?)

Does current service planning and service delivery reflect a whole-systems approach?

- If yes, what best illustrates this?

Is there evidence of the sharing among commissioner and providers of performance and financial data?

What evidence is there of the planning process locally involving:

all relevant organisations (statutory independent sector)

front-line staff

users and carers

### ***Learning disability topic guide***

#### **Initial mapping exercise with professionals and managers**

(To be tailored as appropriate.)

##### ***Preamble***

- Study background
- Current phase of fieldwork
- Reporting arrangements
- Confidentiality/anonymity

##### ***Introduction***

- what is your role in the transition planning process?

##### ***Partners: General***

- which are the key agencies involved in transition?
- which are the key professionals?
- who are the key individuals in this locality?
- what are the strongest relationships?
- what are the less strong relationships?
- what factors promote effective joint working?
- what factors impede effective joint working?

##### ***Partners: Schools/LEA***

- does the school take the lead on transition planning?
- which individual/s take responsibility for writing the plan/s?
- does it involve other agencies effectively?
- what is the relationship between the LEA/individual schools?
- do all relevant children have a transition plan?
- what is the link between children's/adult services planning?

##### ***Lifelong Learning***

- do colleges take a proactive role in lifelong learning?
- what is the relationship between colleges and the Local L&S Council?
- does L&S Council effectively address the transition issue?
- does LEA have a Lifelong Learning Plan with a disability statement?
- is there a Lifelong Learning Partnership convened by LEA?
- do day services link effectively with lifelong learning opportunities?

##### ***Work***

- is advice given on the relationship between work and social security?
- is there a local employment strategy for PWLD?

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- do LD JIP and Welfare to Work JIP relate to one another?
- do JIPs bring appropriate partners together?
- does JIP relate to HIP and Comm. Plan?
- is use made of the Workstep programme?
- are other employment support schemes accessed?
- are any Social Firms planned or in existence?

### ***Day Services/Activity***

- do day services reflect approach of Valuing People?
- do they offer a person-centred approach?
- are they flexibly available in a variety of settings?

### ***Housing***

- is LD addressed in Supporting People programme?
- do housing agencies work closely with others?

### ***Inter-Agency Partnership Mechanisms***

- what use is made of s31?
- what use has been made of Best Value?
- is membership of Learning Disability Partnership Board appropriate for the task?
- does Connexions have capacity to link agencies effectively?
- does Connexions link effectively with Local L&SC?
- does one local body have an overall responsibility?
- has the Learning Disability Partnership Board appointed a transition champion?
- has the Learning Disability Partnership Board appointed an employment champion?
- do the different parts of the transition system fit together?

### ***Inter-Professional Partnership Mechanisms***

- who are the main professionals involved?
- are there any differences in values and culture?
- has the role/membership of CLDT been reviewed?
- has a 'practitioner partnership' been created?

## **Interviews with professionals and managers (second round)**

(To be tailored as appropriate.)

- 1 Problems associated with discontinuities of information and communication: gaps, delays, confusion?
- 2 Problems of discontinuity between children's and adult social services: informational, financial, organisational, chronological?

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- 3 Problems of limited range, and limited degree of involvement, of professionals/service managers in crucial milestones in young people's progression?
- 4 Problem of pronounced discontinuity between child and adult healthcare: access more difficult and many professionals not in post – occupational therapist, SALT, clinical psychology, psychiatry.
- 5 Problem of unclear areas of responsibility and lines of accountability for transition between agencies (Learning Disability Partnership Boards, Connexions Partnerships etc) and between professionals (Connexions PA and Transition Workers).
- 6 Problem of L.D. Transition being everyone's distant relative but no-one's baby: no clarity on lead responsibility and no-one's core business?
- 7 Problem of L.D. being relatively low priority and transitions a low priority within L.D.?
- 8 Problem of new partnerships wanting to deal with new, high-profile issues (e.g. PCP) rather than enduring difficulties and 'wicked issues' like transition?
- 9 Problem of short-term perspective and planning – despite predictability of transition?
- 10 Problem of organisational complexity and environmental turbulence: sheer number of organisations involved, some new and most in organisational flux?
- 11 Problem of too few options available post-college: school – college 'visible' and relatively straightforward, but then transition to what?
- 12 How far would you agree that our overall conclusion (from first-round interviews) still describes the position in your locality?:

*'...transition from adolescence to young adulthood for people with a learning disability is characterised by discontinuity rather than continuity'.*

## **Interviews with young people and parents**

**First round:** Interview conducted by asking people to 'tell their story' using the following general questions (adapt to circumstances):

- what happened when it got close to the time to leave school?
- who helped you in deciding what to do next?
- what sort of things were talked about?
- were you pleased with what happened?
- what has happened since leaving? [where appropriate]
- what do you think the longer-term situation will be?
- do you feel good about the future?

**Second round:** Follow-up interview conducted by asking people to describe events and experiences since the previous interview again using general questions (adapt to circumstances):

- what has happened since leaving school?
- who has helped you with ongoing decisions?
- what sort of things have been talked about?

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- are you pleased with what has happened since we last spoke?
- what has happened since leaving college/other situation post-school?  
[where appropriate]
- what do you think the longer-term situation will be?
- do you feel good about the future?

**Overall:** ask people to articulate carer versus user viewpoints.

## **Disclaimer**

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## **Addendum**

This document was published by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) research programme, managed by the London School of Hygiene & Tropical Medicine.

The management of the Service Delivery and Organisation (SDO) programme has now transferred to the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton. Prior to April 2009, NETSCC had no involvement in the commissioning or production of this document and therefore we may not be able to comment on the background or technical detail of this document. Should you have any queries please contact [sdo@southampton.ac.uk](mailto:sdo@southampton.ac.uk).

Addendum:

This report was amended on 29<sup>th</sup> September 2011 to update the correct copyright statement and/or correct the publication date. The content of the report has not been changed.