

Transition from CAMHS to Adult Mental Health Services (TRACK): A Study of Service Organisation, Policies, Process and User and Carer Perspectives

Report for the National Institute for Health Research Service Delivery and Organisation programme

January 2010

prepared by

Professor Swaran P Singh

Health Sciences Research Institute, University of Warwick

Dr Moli Paul

Health Sciences Research Institute, University of Warwick

Dr Zobia Islam

Health Sciences Research Institute, University of Warwick

Dr Tim Weaver

Division of Neurosciences and Mental Health, Imperial College London

Dr Tami Kramer

Division of Neurosciences and Mental Health, Imperial College London

Professor Susan McLaren

Faculty of Health and Social Care, London South Bank University

Dr Ruth Belling

Faculty of Health and Social Care, London South Bank University

Dr Tamsin Ford

Child Health, Peninsula College of Medicine and Dentistry

Ms Sarah White

Division of Mental Health, St. George's, University of London

Ms Kimberly Hovish

Division of Mental Health, St. George's, University of London

Ms Kath Harley

Division of Mental Health, St. George's, University of London

TRACK Project Steering Committee members: Jenny Dale, Dr Navina Evans, Nicole Fung, Dr Dan Hayes, Dr Bob Jezzard, Dr Anne Rourke, Dr Morris Zwi

Address for correspondence

Professor Swaran P Singh

Health Sciences Research Institute

Warwick Medical School

Gibbett Hill Campus

University of Warwick

Coventry CV4 7AL

E-mail: S.P.Singh@warwick.ac.uk

Contents

Contents.....	3
Acknowledgements	6
1 Introduction.....	7
1.1 <i>Background: review of literature</i>	<i>8</i>
1.1.1 <i>The importance of transition.....</i>	<i>8</i>
1.1.2 <i>The definitions of transition: adolescence to adulthood...10</i>	<i>10</i>
1.1.3 <i>Transition in health care.....13</i>	<i>13</i>
1.1.4 <i>Transition from child and adolescent mental health services (CAMHS) to adult mental health services (AHMS)</i>	<i>14</i>
1.1.5 <i>Barriers to optimal transition</i>	<i>19</i>
1.1.6 <i>Transition from CAHMS to AMHS: gaps in the evidence base</i>	<i>21</i>
1.2 <i>TRACK study: aims & objectives.....</i>	<i>22</i>
2 Stage 1: Audit of Transition Protocols	24
2.1 <i>Aims</i>	<i>24</i>
2.2 <i>Methodology</i>	<i>24</i>
2.2.1 <i>Sample.....</i>	<i>24</i>
2.2.2 <i>Design.....</i>	<i>24</i>
2.2.3 <i>Data collection.....</i>	<i>26</i>
2.3 <i>Analysis.....</i>	<i>27</i>
2.4 <i>Results.....</i>	<i>28</i>
2.4.1 <i>London sites.....</i>	<i>28</i>
2.4.2 <i>West Midland site (Coventry & Warwickshire only)</i>	<i>28</i>
2.4.3 <i>Structure of protocol-sharing units</i>	<i>28</i>
2.4.4 <i>Transition boundary</i>	<i>35</i>
2.4.5 <i>Transition protocols.....</i>	<i>35</i>
2.5 <i>Discussion</i>	<i>39</i>
3 Stage 2: Case note survey of transitions	43
3.1 <i>Aims</i>	<i>44</i>
3.1.1 <i>Definitions</i>	<i>44</i>
3.2 <i>Method/design.....</i>	<i>45</i>
3.3 <i>Data collection tools</i>	<i>45</i>
3.3.1 <i>Case ascertainment.....</i>	<i>45</i>
3.3.2 <i>Phase 1: accessing databases.....</i>	<i>46</i>
3.3.3 <i>Phase 2: contacting clinicians</i>	<i>46</i>
3.3.4 <i>Developing the TRACKING tool.....</i>	<i>47</i>
3.3.5 <i>Data collection.....</i>	<i>47</i>
3.4 <i>Statistical analysis</i>	<i>48</i>
3.4.1 <i>Reliability of data extraction</i>	<i>48</i>
3.4.2 <i>Transition pathways</i>	<i>48</i>
3.4.3 <i>Predictors of achieving transition.....</i>	<i>48</i>
3.4.4 <i>Predictors of achieving an optimal transition</i>	<i>50</i>
3.5 <i>Results.....</i>	<i>50</i>
3.5.1 <i>Case ascertainment.....</i>	<i>50</i>

3.5.2	<i>Transition pathways</i>	52
3.5.3	<i>Sample description</i>	57
3.5.4	<i>Predictors of achieving transition</i>	58
3.5.5	<i>Optimal transitions: cases</i>	66
3.5.6	<i>Optimal transitions: predictors of experiencing continuity of care</i>	70
3.6	<i>Discussion</i>	76
3.6.1	<i>Identifying actual and potential referrals</i>	76
3.6.2	<i>Sample description</i>	78
3.6.3	<i>Transition pathways</i>	80
3.6.4	<i>Predictors for achieving transition from CAMHS to AMHS: actual v potential referrals</i>	83
3.6.5	<i>Optimal or suboptimal transition</i>	84
3.6.6	<i>Predictors of experiencing continuity of care</i>	85
4	Stage 3: Organisational perspectives of health and social care professionals and representatives of voluntary organisations	87
4.1	<i>Aims</i>	88
4.2	<i>Design and Methods</i>	88
4.2.1	<i>Diagnostic analysis</i>	88
4.2.2	<i>Semi-structured interviews</i>	88
4.3	<i>Results</i>	91
4.3.1	<i>Resources</i>	92
4.3.2	<i>Eligibility issues</i>	102
4.3.3	<i>Communication and working practices</i>	107
4.3.4	<i>Service cultures</i>	116
4.4	<i>Discussion</i>	120
4.4.1	<i>Transition: informational continuity</i>	120
4.4.2	<i>Transition: cross boundary and team continuity</i>	121
4.4.3	<i>Transition: flexible and long-term continuity</i>	123
4.4.4	<i>Transition: relational, personal and therapeutic continuity</i>	124
4.4.5	<i>Conclusions</i>	125
5	Stage 4: Case studies	128
5.1	<i>Aims</i>	129
5.2	<i>Method</i>	129
5.2.1	<i>Sampling method</i>	129
5.2.2	<i>Recruitment of the sample</i>	129
5.2.3	<i>Interview method</i>	130
5.2.4	<i>Data management and analysis</i>	130
5.3	<i>Results</i>	134
5.3.1	<i>Characteristics of the sample</i>	134
5.3.2	<i>Preparation for transition</i>	134
5.3.3	<i>Accounts of transition</i>	138
5.3.4	<i>The outcome of transition</i>	143
5.3.5	<i>Other factors impacting on transition process and outcome</i>	146
5.3.6	<i>Respondent-generated suggestions for improvement in transition</i>	151
5.4	<i>Discussion</i>	152
5.4.1	<i>Issues and limitations</i>	152
5.4.2	<i>Transition experiences of service users, carers and mental health professionals</i>	154
6	Discussion	156

6.1	<i>Introduction</i>	157
6.2	<i>Context of transition: service complexity and cultures</i>	161
6.2.1	<i>Service complexity</i>	161
6.2.2	<i>Service cultures</i>	162
6.3	<i>Negotiating the transition boundary</i>	163
6.3.1	<i>Policies and protocols</i>	163
6.3.2	<i>Eligibility criteria</i>	164
6.3.3	<i>Diagnosis</i>	166
6.4	<i>Crossing the transition boundary: optimal and suboptimal transition</i>	167
6.4.1	<i>Joint working</i>	167
6.4.2	<i>Information transfer</i>	168
6.4.3	<i>Therapeutic relationships and family involvement</i>	169
6.4.4	<i>Engagement</i>	170
7	Recommendations	172
7.1	<i>Introduction: mind the gap</i>	173
7.2	<i>Improving the CAMHS/AMHS interface: mind how you cross the gap</i>	173
7.3	<i>Developing a youth mental health service: bridging the gap...</i>	180
	References	183
	Appendix 1: Mapping Tool	194
	Appendix 2: Case note tracking questionnaire for actual referrals	202
	Appendix 3: Case note tracking questionnaire for potential referrals	222
	Appendix 4: Stage 3 interview schedule	237
	Appendix 5: Stage 4 interview schedule for service users	239
	Appendix 6: Stage 4 interview schedule for parents	243
	Appendix 7: Stage 4 interview schedule for CAMHS clinicians	247
	Appendix 8: Stage 4 interview schedule for AMHS clinicians	250

Acknowledgements

The TRACK study group gratefully acknowledges the help, input and cooperation of clinicians, managers and administrative staff from the six study sites. We are also very thankful to all the service users and carers who gave their time and invaluable contribution for the qualitative interviews in study four.

The Report

1 Introduction

Adolescence represents an inner emotional upheaval, a struggle between the eternal human wish to cling to the past and the equally powerful wish to get on with the future. Louise J. Kaplan, psychoanalyst and author

*What I was really hanging around for, I was trying to feel some kind of a good-by. I mean I've left schools and places I didn't even know I was leaving them. I hate that. I don't care if it's a sad good-by or a bad good-by, but when I leave a place I like to know I'm leaving it. If you don't, you feel even worse. J.D. Salinger, *The Catcher in the Rye**

1.1 Background: review of literature

1.1.1 The importance of transition

There has been long standing concern about young people with mental health problems who fall between child and adolescent mental health services (CAMHS) and adult mental health service (AMHS) and may get 'lost' during their move from CAMHS to AMHS (hereby called transition) (Royal College of Paediatrics and Child Health, 2003; Lamb, Hall, Kelvin and Van Beinum, 2008, p6). Disruption of care during transition adversely affects the health, wellbeing and potential of this vulnerable group (American Academy of Pediatrics, American Academy of Family Physicians and American College of Physicians-American Society of Internal Medicine, 2002; Forbes, While, Ullman, Lewis, Mathes and Griffiths, 2002; While, Forbes, Ullman, Lewis, Mathes and Griffiths, 2004; Department of Health, 2006c; Kennedy, Sloman, Douglass and Sawyer, 2007; Department for Children Schools and Families and Department of Health, 2008; Lamb *et al*, 2008). Ideally, such a transition should be a planned, orderly and purposeful process of change from child-oriented to adult models of care (Blum, Garell, Hodgman, Jorissen, Okinow, Orr and Slap, 1993; McDonagh and Kelly, 2003).

Transition is distinct from transfer: the latter refers to termination of care by a children's health care provider which is re-established with an adult provider (Burke, Spoerri, Price, Cardosi and Flanagan, 2008). Transition is more than merely the means of an individual moving from one service to the next, but instead is 'a way to enable and support a young person to move towards and onto a new life stage' (Beresford, 2004, p584). It is a multidimensional, multidisciplinary, lengthy process continuing on into adult care, marked by joint responsibilities in multidisciplinary working (Royal College of Nursing, 2003; Royal College of Paediatrics and Child Health, 2003; HASCAS, 2006; McDonagh and Viner, 2006). It therefore needs to be 'co-ordinated, planned, efficient and smooth' (Conway, 1998, p210). As a 'dynamic process with a beginning, middle and end' (McDonagh, 2006, p3), optimal transition to adult health care should 'support each young person in attaining his or her maximum potential' (Rosen, 2004, p125).

Young people undergoing transition are also negotiating a developmental transition from childhood to adulthood, which generates needs beyond those which are illness-specific (Royal College of Paediatrics and Child Health, 2003; Royal College of Nursing, 2004). Needs related to such developmental transition may remain unmet if the process is seen simply as an administrative event between CAMHS and AMHS (Vostanis, 2005). Transitional care is becoming an important focus for both policy and practice with calls for generic, cross-specialty developments, since many problems which arise at the interface are not specialty- or disorder-specific, but embody common challenges for child and adult services across specialities (McDonagh and Viner, 2006).

In the USA, a survey of transition provision within 41 states found that a quarter of child mental health services and half of adult services offered no transition support (Davis, Geller and Hunt, 2006). Another US study (Davis and Sondheimer, 2005) found that continuity of care was hampered by separate child and adult mental health systems, marked by separate policies for access, lack of clarity in access procedures and lack of shared planning. A recent study from Australia found that many young people referred by CAMHS were not accepted by AMHS, despite having substantial mental health needs and functional impairment (Cosgrave, Yung, Killackey, Buckby, Godfrey, Stanford and McGorry, 2008). An Audit Commission (1999) report in the UK found that less than a quarter of national services have specific arrangements to support transition of care between CAMHS and AMHS.

In the UK, the *National Service Framework (NSF) for Children, Young People and Maternity Services* (Department of Health and Department for Education and Skills, 2004) has delineated several standards for mental health services. These emphasise access to age-appropriate services which are responsive to specific needs of all young people as they attain adulthood. For those with mental health problems, the NSF advocates access to local, multidisciplinary CAMHS teams that ensure effective assessment, treatment and family support. Transition in the NSF for Children and Maternity Services is envisaged as a planned and co-ordinated process around specific needs that aims to maximise health outcomes, life chances, opportunities and the ability to live independently. NSF recognises that providing such transition has implications for workforce capacity, capability and the inception of new roles and training. More recently, the HASCAS (2006) Tools for Transition report highlights the barriers to transition and makes recommendations for improvements to services. Such barriers include variable age boundaries, service configurations, and thresholds for access as well as differing professional cultures within CAMHS and adult services. HASCAS recommends having designated transition (or link) workers, the involvement of young people in the decision making process, focussing and building on young people's strengths, and improving continuity of care through case management, CPAs and enabling young people to make informed decisions through the provision of appropriate information.

Recent policy implementation to reform adult community services also emphasises the need for continuity of care. The NSF for Mental Health (Department of Health, 1999b) focuses on the need to integrate mental health and Social Services to combat fragmentation of services, poor interdisciplinary co-ordination, and user and carer distress arising from service discontinuities (Singh, 2000; Bosanquet and Kruger, 2003; Onyett, 2003). A further impetus to integrate health and social care has been through the formation of care trusts together with the development of care programme and care management approaches (Department of Health, 2000). Integrated, adult community mental health teams (CMHTs) are now considered intrinsic to delivering continuity of care (Department of Health, 2002b). More recent changes in community provision has resulted in

'generic' community mental health teams and specialist 'functional teams' such as early intervention services for first-episode psychosis, assertive outreach teams for difficult to engage users, and home treatment teams to avert hospitalisation and crisis management. Transition between these functional teams also needs to ensure continuity of care. This literature review focuses on transition between CAMHS and AMHS; transitions from one functional mental health team to another and between adult and older adult teams are not included.

1.1.2 The definitions of transition: adolescence to adulthood

The concept of transition in relation to young people can be viewed from three distinct perspectives. Firstly, from a developmental perspective, adolescence is a crucial stage of emotional, psychosocial, personal and physiological developments as young people embark on adult roles through tasks such as separating from family, deciding on a career path and defining self in a social context (Lee, 2001). Secondly, from a health care perspective, young people have to move from one service to another upon reaching certain age milestones. Thirdly, from a situational perspective, individuals experience changes as they move from one institutional environment to another. **In this study we use the term *transition* explicitly to mean health care transition defined as a formal transfer of care from CAMHS to adult services.** However, to understand health care transition in the context of other transitions, we will briefly explore the literature around developmental and institutional transitions in adolescence.

Adolescence: stage or age?

Transition from childhood to adulthood involves crucial changes in social, sexual and identity development that occur over time (Eiser, 1993; Davis, 2003). Broadly speaking, it is a *process* starting with puberty and ending with the assumption of adult roles. There is wide variation between cultures and within cultures over time at the age at which a young person is considered to become an adult (McDonagh, 2006). Galatzer-Levy (2002) has argued against an 'essentialist' view of adolescence and instead suggested that the very existence of this period should be conceived as a social construct. The TRACK study addresses the health care transitions between child and adult models of care. The developmental transition between childhood and adulthood, while relevant, is not the primary focus of the study and will not be considered in this review.

Adolescence is a developmental stage, rather than something defined strictly by age. However, child and adult services are often demarcated by rigid age boundaries. Some authors (e.g. Davis, 2003) refer to the age group of 16-25 as the 'transition group'; in contrast, the Royal College of Paediatrics and Child Health (2003) names 10-20 year olds as adolescents. In its surveys on mental health, the National Office for Statistics groups 16- and 17-year-olds with adults and young people aged 15 and under as children, with no separate category for adolescents (Cooper and Bebbington, 2006) even though adolescents have been recognised as a

health service user group in their own right since the 1950's (Royal College of Paediatrics and Child Health, 2003).

In their study on socially disadvantaged young people, Webster *et al* (2004) state: 'the problems with youth transitions do not conclude at neat, age-specific points and, therefore, age-related policies ... do not "fit" harmoniously with the realities of the extended transitions that [their] sample members have undertaken' (p41). The Social Exclusion Unit (2005) notes that age boundaries that demarcate services 'can seem arbitrary, and often don't give any helpful flexibility to those whose lives aren't following a conventional pattern...' (p52). A consensus is now emerging that health services should consider the health and developmental needs of two groups: children under 12 years and young people aged between 12-24 years (Patel, Flisher, Hetrick and McGorry, 2007).

Why is adolescence a 'risk period'?

The journey into adult life is a time of profound psychological and social change for young people and their families. 'Adolescents' have greater propensity for risk-taking behaviours and the explanations for this range from biological (such as neuroendocrine influences and pubertal events), biopsychosocial (within which risk-taking is understood in relation to exploration, individuation and achieving autonomy) and psychological (e.g. related to establishing a locus of control) (Rolison and Scherman, 2002).

Adolescence is also a risk period for higher psychological morbidity. Overall rates of mental health problems in young people increase with age, problems become more complex, and the more serious disorders such as psychosis emerge (Petersen and Leffert, 1995; Lamb *et al*, 2008). Young people also fall between child and adult services, and have greater likelihood of disengagement from services (Lamb *et al*, 2008).

Young people with mental health problems have the highest rates of long-term morbidity and mortality (Royal College of Paediatrics and Child Health, 2003). A review of 52 studies of the prevalence of childhood and adolescent psychiatric disorders showed a median rate of 8% for preschoolers, 12% for primary school age children, 15% for adolescents and 18% in studies 'with a wider age range' (Roberts, Attkisson and Rosenblatt, 1998). A more recent UK survey found that 10% of 5- to 16-year-olds have a mental health disorder (Green, McGinnity, Meltzer, Ford and Goodman, 2005). In 11- to 16-year-olds the rate of mental health disorders is 12% (Green *et al*, 2005), while up to 20% of 16- to 24-year-olds have a mental health problem, most commonly anxiety and depression (Budd, Sharp and Mayhew, 2003). Attempts at suicide are made by 2-4% of adolescents, and 7.6 per 10,000 15- to 19-year-olds actually succeed. In addition, 2-8% of young people experience major depression; 1.9% have Obsessive Compulsive Disorder; 0.5-1% of 12- to 19-year-olds (predominantly females) have Anorexia Nervosa and a further 1% have Bulimia Nervosa (Department of Health, 1995). Taken together, at least one in four to five young people will suffer from at least one mental disorder in any given year (Patel *et al*, 2007).

Comorbidity is also common in adolescence, both in terms of psychiatric disorder and additional problems. Even in community samples, 20% of those with an impairing psychiatric disorder have more than one disorder, and comorbidity among those attending CAMHS is likely to be even higher (Ford, Goodman and Meltzer, 2003; Ford, Hamilton, Meltzer and Goodman, 2008). The *Breaking the Cycle* report (Social Exclusion Unit, 2004) found that 98% of young adults (16- to 25-year-olds) accessing services in the UK had more than one problem or need. Common comorbid problems included homelessness, problems associated with leaving care, lack of training/education opportunities, barriers to employment, crime, poor housing, drug and alcohol misuse and learning disability. In autumn 2004 there were approximately 5.5 million people aged between 16 and 24 in England; of these, around 750,000 were not in education, employment or training (Office for National Statistics, 2004) and thus more likely to be at risk of developing mental health problems (Mental Health Foundation, 1999; Smith and Leon, 2001; Myers, McCollam and Woodhouse, 2005).

The use and abuse of alcohol and drugs is a significant issue among adolescents: 29% of 13-year-olds report drinking alcohol once a week; 16% of 16-year-olds regularly use solvents or illegal drugs; while 17% of older teenagers use cannabis (Fonagy, Target, Cottrell, Phillips and Kurtz, 2000). Young people with chronic diseases are more likely to engage in risky behaviours, such as smoking, substance misuse and unprotected sexual activity, and to have psychiatric disorders (Green *et al*, 2005; Sawyer, Drew, Yeo and Britto, 2007). For young people receiving child mental health services, the rate of substance abuse or dependence increases dramatically, affecting nearly half of 21- to 25-year-olds (Greenbaum *et al*, 1991, cited in Davis and Vander Stoep, 1997).

These young people will be the next cohort of parents. A great deal of research now links poor and inconsistent parenting with child abuse, neglect, lower academic achievement, higher rates of offending, and conduct disorder (Farrington, 1994). Forty-seven percent of children assessed as having a mental health disorder have a parent with a mental health difficulty such as anxiety or depression. Having a parent with a mental illness increases the risk of children developing a mental illness themselves (Rutter, 1989; Green *et al*, 2005; Royal College of Psychiatrists, 2008). Young women with a psychiatric disorder are six times more likely to get pregnant between the ages of 18-21 than those without such a diagnosis (Wagner, 1995, cited in Davis *et al*, 2006). Teenage mothers also have an increased risk of mental disorder compared with mothers over 20 years of age (Lamb *et al*, 2008).

Mental health problems in adolescence also predict problems in adulthood (Silva, 1990; HASCAS, 2006; Lamb *et al*, 2008). The National Comorbidity Survey Replication in the USA found that 75% of people with a mental disorder had an age of onset younger than 24 years (Kessler, Chiu, Demler and Walters, 2005). Similarly, half of the adults with psychiatric disorder at age 26 in the Dunedin cohort had a psychiatric disorder before the age of 15, increasing to three quarters by age 18, and even further among adults who had contacted services in relation to their psychiatric disorder (Kim-

Cohen et al, 2003). Yet for many years this age group has only received inconsistent attention from services (Reder, McClure and Jolley, 2000; The Children's Commissioner for England, 2007). This group is also more likely to disengage from services, with younger age and comorbid drug use both predicting disengagement from care (Rossi, Amaddeo, Bisoffi, Ruggeri, Thornicroft and Tansella, 2002; Harpaz Rotem, Leslie and Rosenheck, 2004). Adult services deal with service users as individuals, while children's services treat them as part of a system (Social Exclusion Unit, 2004; Singh, Evans, Sireling and Stuart, 2005). With few arrangements in place for young people negotiating transition boundaries, some slip through the care net during transition only to present to adult services later on, by which time they may have developed severe and enduring mental health problems (Vostanis and Richards, 2002; Davis, 2003; Department of Health, 2003).

1.1.3 Transition in health care

Most studies on transitions in health care are from a non-UK perspective or address chronic illness, physical disability and learning disability, e.g. physical disability (Ko and McEnery, 2004); HIV (Miles, Edwards and Clapson, 2004); brain injury (Kent and Chamberlain, 2004); cystic fibrosis (Cowland, 2003); learning disability (Cameron and Murphy, 2002). While *et al* (2004) carried out a systematic review to identify transition practices and good practice models. Of the 126 relevant articles identified and reviewed, only one addressed a mental health population, and that was within a US context. A comprehensive review of this literature is beyond the scope of this study; however, some of the main themes which emerge are outlined below. While evidence from physical health services or from outside the UK may not be generalisable to mental health services in the UK, there are certain lessons which can be learned from this research.

Advances in medical care over the last few decades have led to an increased life expectancy for many young people with chronic illness or physical disability (Department for Children Schools and Families and Department of Health, 2007; Sawyer *et al*, 2007). This in turn has led to higher numbers crossing over from paediatric to adult care. However, in a study examining transitions of young people with congenital heart defects, less than half were found to have made a successful transition to adult services (Reid, Irvine, McCrindle, Sananes, Ritvo, Siu and Webb, 2004). The report *Transition: Getting It Right for Young People* (Department of Health, 2006d) acknowledges the difficulties of such transition and its impact upon of young people under care. Many young people appear dissatisfied with transition arrangements, despite being satisfied with the treatment offered by both child and adult services (DARE Foundation, 2006, cited in Knapp, Perkins, Beecham, Dhanasiri and Rustin, 2008).

Findings from a postal survey of 40 health professionals illustrate the problems of transition in the learning disability and chronic illness fields (Por, Golberg, Lennox, Burr, Barrow and Dennard, 2004). Most respondents felt that 'mental maturity' was the key criterion for assessing a young person's readiness to transfer to adult services (21 out of 40). Other criteria cited included age (two-thirds of participants said children's services should

end at 17-18 years); willingness to be transferred; ability to care for self; level of support; and that the transfer time-point should depend upon the individual and not be prescriptive. Only 10% of participants believed that young people with chronic conditions were adequately prepared for transition. Some professionals, such as nurses from adult services, felt unprepared to take over care of adolescents. Some felt that the parents of service users were 'interfering'. Overall, clinicians wanted to be involved in transition care and decision making and meet young people prior to transfer. They also called for written transfer plans and information packs to be provided to families about the adult services. Similar findings have been reported in other surveys (Reiss and Gibson, 2002; Coleman and Berenson, 2004). Additional ideas proposed include electronic health information systems across child and adult services facilitating easy access to information on service users undergoing transition. Such a plan is apparently in development within the NHS (see www.connectingforhealth.nhs.uk).

Given the pervasive nature of the problems at the child and adult interface it is not surprising that more effective transition arrangements, increased joint working and closer liaison between child and adult services has been recommended in services for both learning disability (Department of Health, 2001) and chronic illness (Reiss and Gibson, 2002). Multi-agency working in health care transitions for young people is prescribed as a core standard in the NSF for Children, Young People and Maternity Services (Department of Health and Department for Education and Skills, 2004), particularly for those with chronic and serious medical conditions (see section 1.1.4 *Transition from CAMHS to AMHS: the policy imperatives*).

1.1.4 Transition from child and adolescent mental health services (CAMHS) to adult mental health services (AHMS)

Delineating service boundaries

CAMHS services are organised along four tiers denoting increasing specialism and case complexity as follows (Health Advisory Service, 1995):

Tier 1: Practitioners who are not mental health specialists, but who work with children in community settings such as general practice, schools, voluntary agencies.

Tier 2: CAMHS specialists who work alone in community and primary care settings and/or with children whose difficulties are milder and/or of recent onset, and/or who would be unlikely to reach traditional secondary level mental health care. These services support professionals working within Tier 1 and have a role in outreach and engagement.

Tier 3: CAMHS specialists who work in specialised multidisciplinary services in community mental health or child psychiatry outpatient settings.

Tier 4: CAMHS specialists who work in tertiary level services in day units, highly specialised outpatient teams, and inpatient unit settings (www.everychildmatters.gov.uk).

One key problem in the UK is a lack of consensus on where CAMHS ends and AMHS begins (Lamb *et al*, 2008). Some services use age cut-offs between 16 and 18 years while others consider CAMHS appropriate only for those in full-time education (Gillam, Crofts, Fadden and Corbett, 2003; Phimister, 2004; Singh *et al*, 2005; Treasure, Schmidt and Hugo, 2005). The Audit Commission (1999) reported that nationally 29% of health authorities commissioned CAMHS for young people up to their 16th birthday only, although adult services were not considered suitable for those under 17. The report highlighted the poor development of adolescent services and their inadequate links with other agencies, including adult mental health services. Indeed, transition boundaries drawn strictly by chronological age are driven by service capacity and limitations rather than what is best for young people.

Tantam (2005) suggests that increasing the age limit for CAMHS to 18 years will 'go some way towards the acknowledged transition problems' with adult services (p141). In contrast is a view that the cut-off when 'adulthood' is reached is difficult to define; hence instead of rigid age demarcations between services, it is better for services to be flexible and consider the developmental needs of individuals (Royal College of Paediatrics and Child Health, 2003; Singh *et al*, 2005; McDonagh and Viner, 2006; Department for Children Schools and Families and Department of Health, 2008; Lamb *et al*, 2008). McGorry (2007) has proposed a youth mental health model, arguing that 'public mental health services have followed a paediatric-adult split in service delivery, mirroring general and acute health care. The pattern of peak onset and the burden of mental disorders in young people means that the maximum weakness and discontinuity in the system occurs just when it should be at its strongest' (ps53).

Barriers at CAMHS-AMHS interface

Ideological, structural, functional and organisational differences between CAMHS and AMHS produce complex challenges for all those involved in negotiating the boundary, including service users, carers and clinicians (Kipps, Bahu, Ong, Ackland, Brown, Fox, Griffin, Knight, Mann, Neil, Simpson, Edge and Dunger, 2002; Singh *et al*, 2005; HASCAS, 2006). CAMHS and adult services differ in their theoretical and conceptual view of diagnostic categories and aetiological processes, in treatment focus, in service organisation, delivery and availability, and in professional training, all of which accentuate the problems at the interface (Reder *et al*, 2000; Singh *et al*, 2005). A Health Select Committee (2000) report identified several problems in transition including the failure of services to work together, the need for care management/planning led by a single practitioner who co-ordinates care across all relevant agencies, shortage of inpatient services for young people, the need for early intervention and poor liaison between various agencies.

Transition from CAMHS to AMHS: the policy imperatives

Following on from the NSF for Mental Health (Department of Health, 1999b), the Healthcare Commission (formerly the Commission for Health Improvement (CHI)) set a key performance indicator entitled: *Transition of Care between CAMHS and Adult Services (2002/2003)* (Commission for Health Improvement, 2003). This included recommendations of the Safeguarding Children's Review (November 2002) and the CHI Child Protection Audit (April 2003). The Emerging Findings of the Children's NSF (Department of Health, 2003) also demanded that CAMHS providers develop robust working protocols to ensure smooth transition of care from CAMHS to AMHS.

In 2002 the Priorities and Planning Framework (Department of Health, 2002a) set a target to 'improve life outcomes of adults and children with mental health difficulties through year on year improvements in access to crisis and CAMH services' and 'reduce the mortality rate from suicide and undetermined injury by at least 20% by 2010' (p11). The Green Paper *Every Child Matters* (Department for Education and Skills, 2004) promised increased investment to deliver a 10% increase in CAMHS each year for the next three years, so that all areas would have a comprehensive CAMHS by 2006, including the implementation of a transition protocol and greater provision of adolescent inpatient beds. The report *Getting the Right Start* (Department of Health, 2003) recommended that all children and adolescent services provide care up until the age of 18.

Subsequently, the National Service Framework for Children, Young People and Maternity Services (Department of Health and Department for Education and Skills, 2004) has recommended that CAMHS should be seeing all children up to their 18th birthday, rather than following arbitrarily drawn service boundaries. It also addresses young people's transitions to adult services within its Core Standard 4: 'Growing up into Adulthood'. This standard emphasises multi-agency transition planning, benefits of joint working between AMHS and CAMHS, involving young people and families in decision making, and improving service users' autonomy. Standard 9 of the Children's NSF ('The Mental Health and Psychological Well-being of Children and Young People') specifically targets services for 16- and 17 year-olds (Department of Health and Department for Education and Skills, 2004). Its priorities include extending CAMHS provision to the 18th birthday, while allowing for flexibility dependent on young people's development and choice, ensuring smooth transition of care and protocols to ensure a flexible but organised approach, staff training, ensuring the dignity and safety of young people admitted to adult mental health units, development of Early Intervention in Psychosis services, and the use of Care Programme Approach on discharge from inpatient care and on transition between CAMHS and AMHS.

Inpatient care for adolescents

Several national policy documents state that ideally no young person under 18 years should be admitted to an adult psychiatric unit, and that inpatient care should be in specialist, age appropriate facilities (The National

Assembly for Wales, 2001; Royal College of Psychiatrists, 2002; Scottish Executive, 2003; Department of Health and Department for Education and Skills, 2004; Scottish Executive, 2005, 2006). In England the NSF for Mental Health (Department of Health, 1999b) states that children and young people should only be admitted to adult psychiatric wards in exceptional circumstances, and requires measures to be in place to safeguard the interests of any young person admitted. A study for the Children's Commissioner for England (2007) highlights the problems associated with admitting young people to adult psychiatric wards and makes recommendations aimed both at preventing inappropriate admission and safeguarding young people admitted to adult wards. It also outlines the Human Rights issues regarding the treatment of children, under the United Nations' Convention on the Rights of the Child (United Nations, 1989).

Most recently, the Mental Health Act 2007 (England and Wales), which amends the 1983 Act, places a duty on hospital managers to ensure that from April 2010, any young person under the age of 18 years, whether detained or admitted voluntarily, is admitted to an environment suitable for their age and need (Department of Health, 2007). In Scotland the mental health delivery plan (Scottish Executive, 2006) has set, as one of its key performance targets, the halving of admissions of under-18-year-olds to adult beds. The Scottish Mental Health Act 2003 (Scottish Executive, 2003) stipulates that age-appropriate facilities, including access to education, must be provided to any young person under the age of 18 admitted under the Act.

Despite the plethora of policy documents and initiatives, there are still variations in service provision for young people with mental health problems, both between regions and within local areas in the UK, leading to inequalities of care provision (National CAMHS Review, 2008). The challenges at the interface between CAMHS and AMHS are not all the responsibility of CAMHS services. These require strategic collaboration between all agencies providing care for adults and children and range from specific local arrangements between CAMHS and AMHS for transition policies, the development of pathways to care and treatment protocols at the interface, to broader national initiatives to improve workforce capacity and training.

Transition and continuity of care

Continuity of care in mental health services is increasingly recognised as a key aspect of service provision (Crawford, de Jonge, Freeman and Weaver, 2004; Department of Health and Department for Education and Skills, 2004; Joyce, Wild, Adair, McDougall, Gordon, Costigan, Beckie, Kowalsky, Pasrheny and Barnes, 2004; While *et al*, 2004) including for those with mental illness (Adair, McDougall, Beckie, Joyce, Mitton, Wild, Gordon and Costigan, 2003; Adair, McDougall, Mitton, Joyce, Wild, Gordon, Costigan, Kowalsky, Pasmeny and Beckie, 2005; Laugharne and Priebe, 2006). While often discussed, continuity of care is not always clearly defined (Freeman, Shepperd, Robinson, Ehrich and Richards, 2000; Freeman, Weaver, Low, de Jonge and Crawford, 2002). Freeman and colleagues (2000) have

summarised the principal characteristics of continuity of care in a 'multi-axial definition' comprising: experienced, cross-boundary, flexible, information, relational and longitudinal continuity. In a subsequent study of continuity in mental health settings (Freeman *et al*, 2002), they added two further definitions, contextual and long-term (See Box 1, from Burns, Catty, Clement, Harvey, Jones, McLaren, Rose, White and Wykes, 2007, p4).

Box 1. Multi-axial definition of continuity of care

Generic (Freeman *et al*, 2000)

Experienced: experience of a co-ordinated and smooth progression of care from the user's point of view

Flexible: to be flexible and adjust to the needs of the individual over time

Cross-boundary: effective communication between professionals and services and with service users

Information: excellent information transfer following the service user

Longitudinal: care from as few professionals as possible, consistent with other needs

Relational: to provide one or more named individual professionals with whom the user can establish and maintain a therapeutic relationship

Mental health-specific (Freeman *et al*, 2002)

Long-term: uninterrupted care for as long as the service user requires it

Contextual: care which should sustain a person's preferred social and personal relationship in the community and enhance quality of life

Other definitions and components of continuity of care have also been suggested. Bindman *et al* (2000) consider continuity of service provision, breaks in service delivery, and regular contact with individual clinicians as measures of continuity. Fortney *et al* (2003) measure continuity through timeliness, intensity, comprehensiveness and co-ordination of service provision, relationship stability between the service user and provider as well as frequency, quantity and locational consistency of encounters, variety of services and case management.

Reviewing the literature, Haggerty *et al* (2003) concluded that continuity of care in mental health services differs from health care provision in its explicit and much greater emphasis on continued contact between service users and professionals. In another review, Joyce *et al* (2004) identified flexibility, access, availability, comprehensiveness of services, and 'longitudinality' as key attributes. Overall, the most important element of continuity of care appears to be service users' experience of continuity (Freeman *et al*, 2002).

In reviewing transition from child to adult services, While *et al* (2004) identified four models of continuity, based on the above definitions proposed by Freeman *et al* (2000; 2002). A *direct transitional model*, based on cross boundary and team continuity, emphasises communication and

information sharing across vertical levels (child to adult services) and horizontal levels (multiple services and agencies). Flexible and longitudinal continuity forms the basis of a *sequential transition model*, cognisant that the care needs of young people change and a period of preparation is needed to promote successful adjustment, requiring extension of child services or joint working between adult and child services. The *developmental transition model* actively focuses on personal growth and development and the support which young people need in order to experience adult care in a positive and effective way. Finally, a *professional transitional model* focuses on the need for professional expertise (child or adult) to respond to young people's needs, ensuring personal, relational and therapeutic continuity are maintained. These models are not mutually exclusive (While *et al*, 2004) and are meant to highlight the key elements of service delivery which can inform good practice and promote continuity of care during transition.

1.1.5 Barriers to optimal transition

McDonagh (2006) has identified several barriers to optimal transition (see Box 2). These include changes in established, long-term therapeutic relationships between young people and health professionals; differences between adult and child models of care; young people's level of maturity and understanding; differing perceptions of the adult care system; adolescent resistance to transfer; family stressors; inadequate education and training for adult care providers on adolescent disorders; and lack of organisational support (Lotstein, McPherson and Strickland, 2005; Burke *et al*, 2008).

Box 2. Barriers to optimal transition

Time

Training of professionals involved

Financial

Different perceptions of young person, parents, and providers (both CAMHS and AMHS)

Attitudinal

Discomfort of professionals involved

Lack of applicability

Difficulty accessing resources

Poor intra-agency co-ordination

Poor interagency co-ordination

Difficulties addressing parental issues

Adolescent resistance

Family resistance

Lack of institutional support

Lack of planning

Lack of appropriate adult specialists

Additional barriers to transition specific to mental health services include lack of local protocols and procedures to guide transition (Treasure *et al*, 2005), lack of collaboration between services, and ineffective interagency working.

Barriers for special groups

Neurodevelopmental disorders

For children with disabilities transition 'from childhood to adulthood is more complex, extremely problematic and, in many cases, highly unsatisfactory' (Beresford, 2004, p582). The situation for young people with a learning disability is particularly complex. They may not meet the eligibility criteria for either the Adult Learning Disability Service or the Adult Community Mental Health Team, yet require ongoing support and psychiatric intervention. This also occurs commonly with high-functioning young people with an autism spectrum disorder or Asperger syndrome, especially in the absence of clear-cut comorbid psychiatric disorder (Lamb *et al*, 2008). There is also growing recognition of inadequate services for young people with Attention Deficit Hyperactivity Disorder (ADHD)/Hyperkinetic Disorder, which is estimated to affect about 4% of the population (Nutt, Fone, Asherson, Bramble, Hill, Matthews, Morris, Santosh, Sonuga-Barke, Taylor, Weiss and Young, 2006). These problems with transition have also been identified in the Department for Children, Schools and Families and Department of Health (2007) transition guide for services for disabled young people.

Acute presentations

Many transitions are unplanned and result from acute, unanticipated and crisis presentations. These presentations can be at times (e.g. out of hours) or places (e.g. at emergency departments) where clinicians are unlikely to have an ongoing relationship with the service user. Alternately, transfers happen so quickly that formal procedures cannot be implemented in time (Coleman and Berenson, 2004).

Young people in special circumstances

Many young people in special circumstances (such as the Looked After or those leaving Local Authority care; the homeless) and from certain minority groups such as asylum seekers and those from a Traveller background may be particularly vulnerable to mental health problems. Pathways and access to mental health care are particularly problematic for people from Black and Minority Ethnic backgrounds (Singh and Grange, 2006; Singh, Greenwood, White and Churchill, 2007). Such groups may not access either CAMHS or AMHS (Richards and Vostanis, 2004). Others, such as those with a forensic history or with significant risk to others, have complex needs and yet may

not meet eligibility criteria of community services. These groups are particularly vulnerable to problems during transition (Lamb *et al*, 2008).

The effect of poor transition

The most disruptive outcome of poor transition is that young people with ongoing needs disengage from services during the transition process. Disengagement from mental health care is in many cases a major problem, with between 30%-60% of young people dropping out of treatment over time (Harpaz Rotem *et al*, 2004). Young, socially isolated males are most likely to disengage from services despite having the greatest need for services (Crawford *et al*, 2004). The most vulnerable therefore are at greatest risk of dropping out of care. Young people are also less likely to collaborate with clinicians about their treatment (Laugharne and Priebe, 2006), partly because many young people feel that they do not have an adequate 'say' in the care they receive (Barker *et al*, 1996, cited in Laugharne and Priebe, 2006). Poor transition simply adds to the risk of such disengagement.

In mental health care, young service users and their carers often have very different perspectives on treatment goals and outcomes from those of clinicians (Perkins, 2001; Garland, Lewczyk-Boxmeyer, Gabayan and Hawley, 2004). Additionally, when young people turn 18 mental health services are no longer obliged to involve their parents or carers in treatment due to the assumed autonomy of the 'adult' service user. Studies show that families feel left out of the treatment process following transition and involving families collaboratively reduces the risk of disengagement as well as carer distress (e.g. Dixon, Adams and Lucksted, 2000; Pitschel-Walz *et al*, 2001, cited in Mottaghipour, Woodland, Bickerton and Sara, 2006).

1.1.6 Transition from CAHMS to AMHS: gaps in the evidence base

Our review confirms the observation that transition is 'discussed frequently but studied rarely' (Reid *et al*, 2004, pe198). Recent reviews of continuity of care also comments upon the paucity of high quality research in this area (Forbes *et al*, 2002; HASCAS, 2006). While mental health service evaluation has improved greatly in its methodology and scope, understanding the relationships between service processes and user outcomes is still limited (Johnson, Prosser, Bindman and Szmukler, 1997). The exception is a recent study, ECHO, that evaluated organisational cultures, structures, processes and resources which influence continuity of care and outcomes for adult service users (Burns *et al*, 2007).

ECHO examined continuity of care in two cohorts – users with psychosis and without psychosis – with continuity measures generated by users and carers. These measures underwent rigorous psychometric assessment, making them the first of their kind, and reflected respondents' priorities. The study used these measures as well as medical records to assess experiences of continuity for both groups, totalling 288 service users. Data were also collected on 107 carers, followed by qualitative interviews with a

sub-sample of service users and carers. A comparative diagnostic analysis was conducted, based on questionnaires and interviews with professionals in NHS trusts, General Practices, and voluntary sector organisations. Findings revealed that barriers to informational, cross boundary, relational and long-term continuity were poor communication underpinned by lack of computing systems which impeded information transfer in joined up working; conflicts in cross boundary work resulting from problems in demarcation of professional role identities; lack of education and training opportunities for staff; use of medical decision-making models which did not maximise a range of professional inputs; staff shortages; inadequate accommodation for users and poor change management during service re-organisation (Burns *et al*, 2007; Belling, Whittock, McLaren, Burns, Catty, Rees Jones, Rose and Wykes, 2008).

Users participating in the ECHO study reported a range of positive and negative experiences in their engagement with the service, a notable barrier being that of 'depersonalised transition' (Burns *et al*, 2007). This occurred during transition between teams as services were re-structured, transition between teams during change of residence, and transition at discharge. Service users sometimes did not know who their key-worker was and felt that they were 'left dangling in unknown territory' with new teams and services that responded to crisis rather than providing preventive support (p195). The findings from ECHO provide important clues for conducting a study on transition from CAMHS to AMHS, since ECHO deals with interagency and cross boundary issues that influence continuity of care.

There are clearly significant gaps in our knowledge about the process, outcomes and experience of transition from CAMHS to AMHS in the UK. While such transition is widely accepted as a critical aspect of continuity of care, we do not know who makes such a transition, what are the predictors and outcomes of successful transition, and what organisational factors facilitate or impede successful transition. Significantly, we also do not know how the process of transition is experienced by clinicians, carers and, most importantly, young service users. Without such evidence, we cannot develop and evaluate specific service models that promote successful transition or plan future service development and training programmes. The TRACK study was designed to answer some of these questions in the UK context.

1.2 TRACK study: aims & objectives

The overall aims of the TRACK study are to:

- (a) identify the organisational factors that facilitate or impede effective transition between Child and Adolescent Mental Health Services (CAMHS) and Adult Mental Health Services (AMHS) and;
- (b) to make recommendations about the organisation and delivery of services that promote good continuity of care.

The specific objectives of the study were to:

- (1) Conduct an audit of the policies and procedures relating to transition within six mental health trusts in London and the West Midlands (three trusts in each region) (Stage 1);
- (2) evaluate the process of transition by a case note survey identifying all actual and potential referrals* from CAMHS to AMHS in the preceding year, 'track' their journey and outcomes in terms of referral and engagement with adult services, and determine the predictors of successful transition (Stage 2);
- (3) conduct qualitative interviews across organisational boundaries and services within health and social care agencies to identify specific organisational factors which constitute barriers and facilitators to transition and continuity of care (Stage 3) and;
- (4) explore the views of service users, carers and mental health professionals on the process of transition experience by a sample of service users (Stage 4).

*Potential referrals included those cases that are considered to need transition but are not transferred to adult services for lack of adequate service provision, or other reasons such as when young people with challenging behaviour are not considered to have a diagnosable (adult) mental disorder or for young people with learning disabilities.

2 Stage 1: Audit of Transition Protocols

'There is a transition protocol which is out of date and is being reviewed, so that might have been part of it. Sometimes you can't even get past the CMHT secretary if the young person isn't 18.' - Psychiatric Nurse, AMHS

2.1 Aims

The specific aims of Stage 1 of the TRACK study were to conduct a content analysis of the available transition policies in Greater London and the West Midlands; and to determine the annual transition rates from CAMHS to AMHS. The focus on protocols originated from The Emerging Findings of the Children's NSF (Department of Health, 2003), which demanded that CAMHS providers develop robust working protocols to ensure smooth transition of care from CAMHS to AMHS.

2.2 Methodology

2.2.1 Sample

We conducted an initial mapping exercise to identify transitions policies across the whole of Greater London. Mapping in this context involved compiling an inventory of transition protocols based upon protocol-sharing units; this was not a mapping of CAMHS provision in the region. The findings of that exercise have already been reported (Singh, Paul, Ford, Kramer and Weaver, 2008). Further mapping of protocols then occurred in the following areas of the West Midlands Region: Birmingham, Solihull, Coventry and Warwickshire. Here we summarize findings from all of Greater London and the West Midland sites. The original project funding did not cover mapping of the Birmingham & Solihull areas and data here were collected by two Specialist Registrars in Psychiatry.

2.2.2 Design

Developing the mapping tool

A literature review of transition from CAMHS to AMHS was undertaken through searches of Medline, EMBASE, CINAHL, PsychINFO, The Cochrane Library, International Bibliography of Social Sciences (IBSS), National Research Register, the HEA Database, and reports and publications from the Department of Health and charities such as YoungMinds and Rethink. Based on the review, a semi-structured study tool was developed which comprised of two parts: the first sought information on respondent structure and organisation (see details below). For the purposes of this study, a

respondent CAMHS was defined as a 'provider agency that provides CAMHS tier 2/3/4 services with shared transition protocols and procedures'. The questionnaire specified that 'if within your service some teams use different protocols or procedures for transition, please count each group of teams using a shared transition procedure/policy/protocol as a distinct service'. The second part collected information about local transition protocols, process and estimates of the average annual numbers of young people who were considered suitable for transfer to AMHS, were actually accepted by AMHS and who remained with CAMHS beyond the transition boundary.

The pilot questionnaire was discussed with two CAMHS consultants in London to help establish face and content validity. The tool collected data on:

type of service (e.g. whether specialist Adolescent Mental Health Service or CAMHS caring for both children and adolescents)

catchment area

staff profile

numbers of referrals received in the previous 12 months

number of currently open cases

the type of adult mental health services the service referred to

number of adult mental health services the service referred to

number of young people, on average, per year, who were kept within CAMHS care past the transition boundary

whether there was a transition protocol in place (a copy of any transition protocol was requested)

whether there was a protocol in place for the management of the interface between CAMHS and the AMHS (if separate to the transition protocol)

whether there was a discharge protocol

number of potential referrals to AMHS per year on average (i.e. those cases that are considered suitable for transition but are not transferred to adult services for lack of adequate service provision, or other reasons such as when young people with challenging behaviour are not considered to have a diagnosable (adult) mental disorder or for young people with neuropsychiatric disorders such as ADHD)

number of actual referrals (i.e. the number of young people whose referrals were actually accepted by the AMHS)

open question – 'Any further comments?'

The response from London services suggested that the original mapping tool needed revision to make it more user-friendly. An amended version, which

sought the same information as the original, was developed for use in the West Midland sites. This also sought additional information about all service users who had crossed the transition boundary in the preceding year, i.e. those who were or could have been transferred to adult services, were requested. This amended questionnaire was again reviewed by two CAMHS consultants, and a final semi-structured study tool agreed (see *Appendix 1* for the Mapping Tool).

2.2.3 Data collection

The task of mapping transition policies and procedures of CAMHS was complicated by the size, structure, levels of specialism of CAMHS and their relationship within health and social care trusts. The process of data collection therefore varied between sites; hence the London and West Midlands region processes are described separately.

Greater London sites

Between August and December 2004 a mailing list of CAMHS that potentially referred to AMHS was compiled using several sources of information including the National CAMHS Support Service (hosted by the DoH, London), CAMHS leads at London Development Centre for Mental Health and from consultant psychiatrists and service managers within various trusts. Data were collected from these CAMHS leads between January and April 2005 including data on actual and potential referrals in the preceding year (September 2003 - August 2004). The mapping tool was sent along with a letter explaining the study and asked to complete the questionnaire in consultation with the multidisciplinary team. A list of services included in the mapping was also sent and respondents asked to contribute to this list if they felt that any other relevant services had been missed. Any further services thus identified were also recruited into the study. Initially respondents were targeted at a trust level but it soon became necessary to target at an individual team level in order to increase the response rate; therefore, a second and then a third mail-shot were sent out. Follow-up phone-calls, emails and faxes helped to increase the response rate as well as consolidate links with teams. Some respondents attributed delays in response or reluctance to respond to the fact that many NHS staff frequently complete numerous questionnaires and/or audits as part of their duties. Two further reminder postal requests, supplemented by follow-up telephone calls, were conducted to improve recruitment rates.

West Midland region sites

In the West Midlands region, Coventry and Warwickshire had been included in the original proposal and were part of the funded project. When the project began, it became clear that Birmingham and Solihull had particular problems in the interface between CAMHS and AMHS and the study team decided to extend the study to this area. A request for further funding request was denied so we decided to collect data from Birmingham and Solihull with the help of two specialist registrars, one from CAMHS (NF) and the other from AMHS (JD).

Coventry & Warwickshire region: A mailing list of CAMHS that potentially referred to AMHS was compiled from July to November 2006 using the CAMHS mapping exercise atlas (Department of Health, 2006b) which had been unavailable when the London site study was planned. In addition, advice was sought from consultant psychiatrists and service managers in regional trusts. The TRACK project was presented at CAMHS team meetings to inform clinicians about the study and garner support. Key professionals including team leaders and service managers were identified. As there were only three CAMHS in the study region, it was agreed with clinicians that responses should be sought at a service level rather than a team level. Data were collected on the mapping tool between November 2006 and October 2007 with data on actual and potential referrals for the 12 month period between January to December 2006

Birmingham and Solihull region: A mailing list of CAMHS teams that potentially referred to AMHS was compiled from September to November 2006 using advice from consultant psychiatrists and service managers in mental health and children's trusts. Nine relevant CAMHS were identified. The study was first presented in November 2006 at an educational meeting for CAMHS staff and received a favourable response. The Mapping Tool was distributed and sent out to the relevant lead clinicians within the nine CAMHS. No responses were received. A reminder was sent by post, supplemented by follow-up telephone calls. Again, no responses were received, so a second presentation was held in March 2007. Again the study received a favourable response from attending clinicians. It was suggested that the Mapping Tool be sent to 16 individual consultant psychiatrists and this was done. A reminder letter and supplementary telephone calls were made. However, only six questionnaires were returned, of which three questionnaires were significantly incomplete and none enclosed a transition protocol. After two further rounds of reminder letters but still no response, in November 2007 the TRACK steering group agreed that data collection from Birmingham and Solihull should be abandoned. Data from Birmingham and Solihull is therefore not presented in the results section. All Tier 4 services in the West Midlands region sub-sample were within Birmingham and Solihull and hence no data on Tier 4 services were available from the West Midlands.

2.3 Analysis

Protocols were subjected to content analysis. Key transition-related themes had initially been identified from a specific policy document (Department of Health, 2003); the transitions literature; sample transition protocols obtained from trusts outside London; and clinicians working in CAMHS in South West London & St. George's Mental Health Trust. Themes identified (e.g. transition boundary) were allocated to pertinent procedural concepts (e.g. transition criteria and service boundaries). Counts of protocols containing specific themes were thereby generated per procedural concept.

The survey questionnaire quantitative data were entered into SPSS. Summary statistics are presented as appropriate. Categorical variables are

presented as frequencies and percentages, continuous variables using means, standard deviations and minimum to maximum values.

2.4 Results

2.4.1 London sites

By April 2005, we had identified 65 CAMHS in Greater London, from which we received 42 (64.6%) completed questionnaires. Responses identified 15 protocols of which two were draft versions.

Respondents (n=42) were located in 11 health trusts, with each having at least five teams (range=5-41, mean=15.7) per CAMHS. Of the non-responding trusts, 78% CAMHS comprised of only one team. Respondents therefore came from most of the larger CAMHS. Respondents described themselves as 'CAMHS' (20), adolescent mental health services (12), specialist CAMHS (1), specialist adolescent mental health services (2), inpatient CAMHS (1), inpatient adolescent mental health service (1), national CAMHS (4) and national inpatient CAMHS (1), serving populations ranging from 60,000 to 4 million, having 1-37.5 whole-time equivalent staff (mean 10.9, SD 9.02, n=41) and having between 10 and 1500 currently open cases (mean 438.32, SD 469.56, n=31).

2.4.2 West Midland site (Coventry & Warwickshire only)

In the West Midlands Region, five mapping tools were completed on behalf of six CAMHS teams. Within the region there were three transition protocols, of which two were draft versions. Respondents (n=5) were located in three trusts, although the mental health services merged into one trust partway through the study. Each trust had two teams per CAMHS. Respondents described themselves as 'CAMHS' (3), Specialist CAMHS (1), and CAMHS/Looked After Children (one mapping tool was completed on behalf of both teams, i.e. the service) and therefore there was a 100% response rate. Respondents reported serving populations ranging from 250,000 to 533,000, having 1-42.6 whole-time equivalent staff (mean 18.18, SD 16.45, n=5) and having 1000 and 3000 open cases (mean 2000; n=2). None of the respondents identified service users who were considered suitable for transition (see section 3.5.1 *Main Limitations*).

2.4.3 Structure of protocol-sharing units

London sites

We received 15 protocols of which two (protocols 5 and 12) were draft versions. They did not cover the whole of Greater London. In addition, we did not find that single CAMH services always generated a protocol each. We therefore use the term 'protocol-sharing unit' to refer to whatever CAMH unit (team, locality, service, trust) or combination of units shared one particular protocol. The protocol-sharing units varied greatly. Protocol 6 was shared by two trusts providing CAMHS, including generic, targeted and

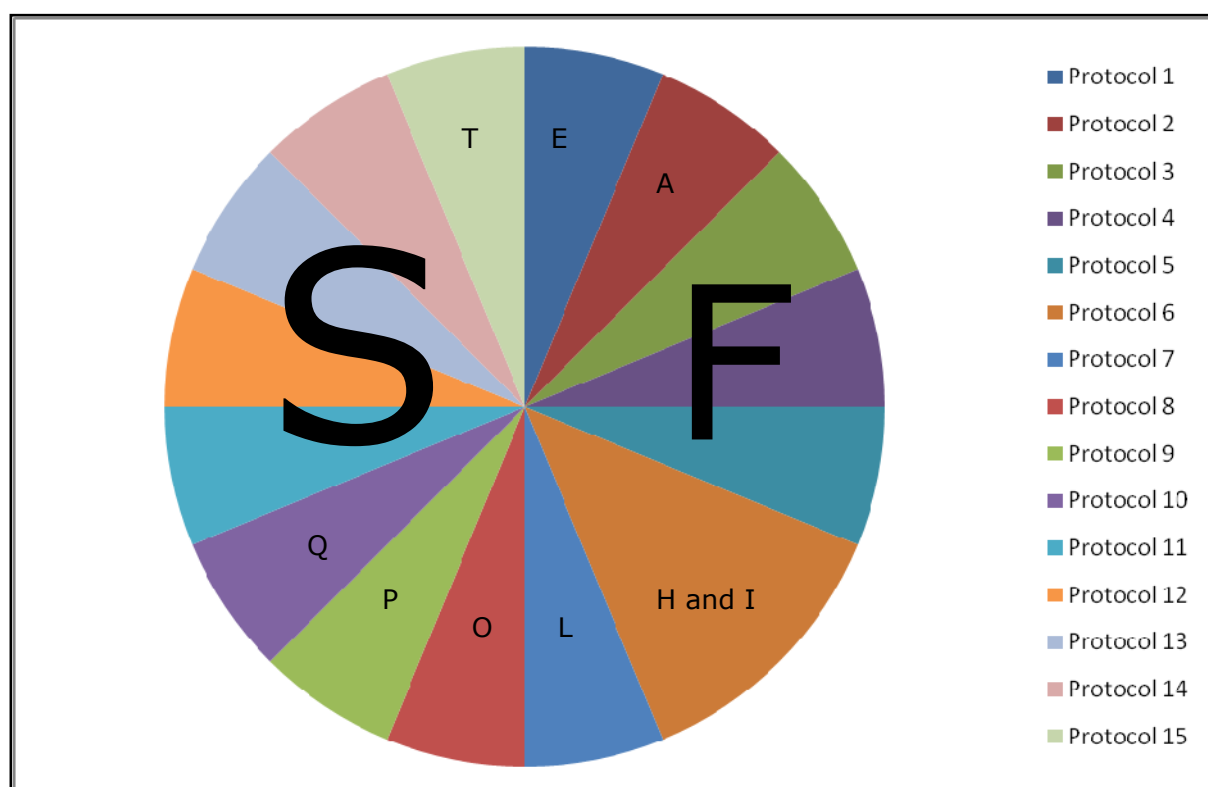
inpatient teams. Protocols 1, 2, 7, 8, 9, 10 and 15 each covered teams within one trust. In relation to these protocols, responding teams within each protocol-sharing unit varied between being generic, locality teams (protocols 1, 9 and 15); generic teams at locality and wider than locality level (protocol 2); locality-based, adolescent teams targeting specific conditions (protocol 8); a generic team providing for 14- to 30-year-olds at wider than locality level (protocol 7); and generic and targeted locality teams alongside national targeted and tier 4 teams (protocol 10). Within another trust each of the four generic teams covering different localities had a protocol of their own (protocols 11, 12, 13, and 14). Within another trust three generic locality teams covering the same locality shared one protocol (3); an inpatient unit covering this locality and other areas used two protocols (3 and 5); and a specialist adolescent team covering one London borough used another protocol (protocol 4). Table 1 illustrates identified transition protocols in Greater London in the context of CAMHS teams, trusts and strategic health authorities. Figure 1 illustrates the distribution of these protocols between trusts identified in Table 1.

Table 1. Identified Transition Protocols in London in the Context of CAMHS Teams, Trusts and Strategic Health Authorities

STRATEGIC HEALTH AUTHORITY	NHS TRUST	CAMH SERVICES	CAMHS TEAMS P**	PRO-TOCOL	TRACK RESPONDING TEAM TYPE* / CATCHMENT AREA / SPECIFICALLY FOR YOUNG PEOPLE (ADOLESCENTS)*	NUMBER OF CMHTS REFERRED TO
1	A	1	3/10	2	• Generic MD/locality d/no	3
					• Generic MD/wider/no	
					• Tier 4 (inpatient unit 0-12yrs)/national/no	
	B	1	0/1			
	C	1	0/1			
	D	1	0/1			
	E	1	5/22	1	• Generic MD/locality a/no	
					• Generic MD/locality b/no	5
					• Generic MD/locality c/no	3
					• Generic MD/locality c/no	1
					• Generic MD/locality c/yes	3
2	F	1	6/25	3	• Generic MD/locality f/no	5
					• Generic MD/locality f/no	3
					• Generic MD/locality f/yes	8
				3+5	• Tier 4 (inpatient unit)/locality e,f,g/yes	

				4	• Targeted (Education-based)/ locality e/yes	5
					• Targeted (Drug and alcohol)/locality ?/no	6
	G	1	0/6			
	H	1	1/5	6	• Targeted (condition-specific)/national/ no	2
	I	1	4/7	6	• Generic MD/locality h/no	1
					• Generic SD/locality h/no	
					• Tier 4 (outreach) /locality h/yes	4
					• Tier 4 (inpatient unit)/wider/yes	10
	J	1	0/1			
	K	1	0/2			
	L	1	1/14	7	• Generic MD/wider/yes (14-30 years)	
3	M	1	0/1			
	N	1	0/1			
	O	1	3/26	8	• Targeted (adolescent service) /locality i/yes	4
					• Targeted (complex mental health needs) /locality j/yes	4
					• Targeted (substance misuse) /locality I,j+/yes	
	P	1	1/15	9	• 1 Generic MD/locality k/no	
4	Q	1	10/27	10	• Generic MD/locality l/no	5

					• Generic MD/locality m/no	3
					• Generic MD/locality n/no	
					• Generic MD/locality o/no	3
					• Generic MD/locality p/no	3
					• Generic MD/locality n/yes	6
					• Targeted (children with moderate to severe learning disabilities)/ locality l,m,n,o,p/no	
					• Targeted (for deaf children)/national/no	3
					• Tier 4 (inpatient unit)/locality l,m,n,o,p /yes	3
					• Tier 4 (inpatient eating disorder unit)/national/no	
5	R	1	0/1			
	S	1	4/45	11	• Generic MD/locality t/yes	
				12	• Generic MD/locality s/yes	
				13	• Generic MD/locality r/yes	5
				14	• Generic MD/locality q/yes	3
	T	1	4/10	15	• Generic MD/locality u/no	2
					• Generic MD/locality u/no	
					• Generic MD/locality v/no	1
					• Generic MD/locality w/no	3

Figure 1. Distribution of protocols between trusts in Greater London

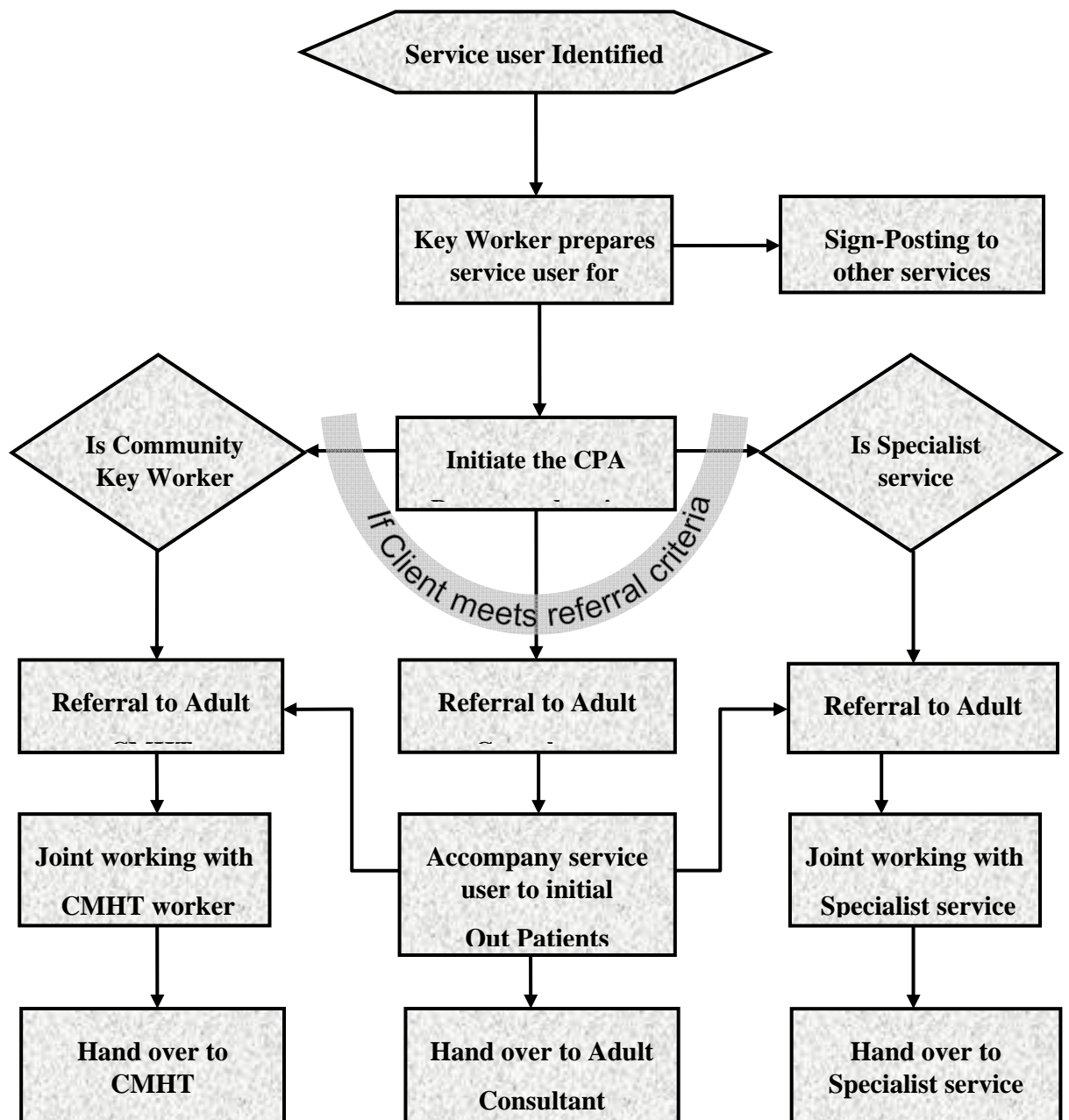
*Letters within the pie chart refer to the trusts as identified in Table 1.

West Midlands region sites

There was one operational protocol within use in West Midlands. There were two additional draft protocols, largely based on the neighbouring area's operational protocol. The three protocols covered the whole of Coventry and Warwickshire. A Transitional Steering Group, consisting of both CAMHS and AMHS members, had developed the operational protocol in December 2003. Figure 2 below, taken from the operational protocol, illustrates the agreed procedures.

Figure 2. CAMHS to AMHS referral: agreed procedures (from Coventry and Warwickshire protocol)

Mental Health CAMHS to AMHS Transition



2.4.4 Transition boundary

London sites

The transition boundary between CAMHS and AMHS varied, with 18 years being the modal boundary (n=25). Among the other protocols, the transition boundary varied as follows: 16-years (n=2); 17-years (n=1); 16-years if not in full-time education (NIFTE) or else 18-years (n=5); 17 if NIFTE or else 18-years (n=2); 18-years, but up to 19 for young people with certain diagnoses (n=1); 19-years (n=2); 20-years (n=1); and over 21-years (n=1). One responding team provided a service for children and not for young people and therefore did not have an interface with AMHS.

The responding teams' estimates of their average annual number of cases considered suitable for transfer to AMHS ranged between 0 and 70 (mean 12.3, SD 14.5, n=37). Estimates of their average annual number of cases that actually made the transition ranged from 0 and 50 (mean 8.3, SD 9.5, n=33). Average numbers of service users who continued to be seen by the team beyond the transitional boundary varied from 0 to 64 (mean 7.6, SD 11.8, n=31).

West Midland region sites

The transition boundary between CAMHS and AMHS was variable and described mostly as 'depending on need': '17-18 dependant on need' (n=1); '17 in most cases' (n=1), and '19 in most cases' (n=1). One respondent provided a fixed boundary of 19 years of age (n=1). One respondent did not answer this question.

Only one respondent estimated their team's average annual number of cases considered suitable for transfer to AMHS each year, giving an average figure of 10, and the number of referrals accepted by adult services, giving an average figure of between 10 and 15 (we noted that the upper estimate is higher than the average number considered suitable for transfer to AMHS). Two teams reported the number of service users who continued to be seen by the team beyond the transitional boundary with one estimating 10 and the other as 'several based on need'.

2.4.5 Transition protocols

London sites

Only the 13 agreed protocols were subjected to content analysis – a research method used to find the frequency of terms or concepts in order to make inferences about their meanings and contexts. Draft protocols were excluded from content analysis since we wanted to capture information about ongoing practice. There were several broad similarities between the stated principles of the protocols. Most referred to the National Service Framework documents (Department of Health, 1999b, 2003; Department of Health and Department for Education and Skills, 2004) and identified the following factors as important in ensuring smooth transition between

services: consistency in service, continuity of care, a seamless transition, clarity about professional's roles and clinical responsibility, information sharing between agencies, aligning of assessment processes between services, resolution of eligibility and funding criteria, joint working preceding final transfer, co-operation & flexibility, user and carer involvement in decision making, care based on the principle of informed consent and consideration of the most appropriate care provision for a young person. All protocols considered an enduring mental health problem or the likelihood of mental health needs continuing into adulthood as important criteria for referral to AMHS. There was therefore very little variation in the stated principles underpinning the protocols. Table 2 summarises the key differences between protocols.

Table 2. Identified differences between transition protocols across Greater London

Protocol theme n=13	n (%)	Further details n (%)
Agencies involved in developing protocol	Not specified: 8(62%) specified: 5 (38%)	Where specified, between two (CAHMS and adult services) and six agencies (CAHMS, AMHS, PCT, Social Services, Information technology and Voluntary sector) had been involved in developing a protocol
CPA used as transition criterion	No: 10 (77%) Yes: 3 (23%)	Generally, service users on Enhanced CPA were considered appropriate for transfer to AMHS and those on Standard CPA would 'be considered'
Transition boundary: 18 th birthday	Yes: 9 (69%) No: 4 (31%)	Transition boundary at: -16 th birthday (n=2) or 17 th (n=1) birthday if service user in full time education (FTE), - 18th birthday if in FTE -21 st birthday: 1 (8%)
Transition boundary flexible	Yes: 10 (77%) No: 3 (23%)	
Specified duration of transition planning	No: 1 (8%) Yes: 12 (92%)	Specified duration of transition planning: -6 (46%) at least 6 months -2 (15%) at least 3 months -4 (31%) at CAMHS review prior to transition
Joint planning meeting	At least one: 11 (85%)	Only joint work mentioned in 2 (15%)
Formal transition plan to be drawn up	Not specified: 5 (38%) Specified: 8 (62%):	Where specified: -5 (38%) before first appointment with AMHS -2 (15%) following assessment by AMHS -1(8%) basic plan before and final plan after assessment by AMHS
Multi-agency involvement in transition planning	Not specified: 5 (38%) Specified: 8 (62%)	Where specified: -6 (46%) a general remark -2 (15%) specified inclusion in decision-making and information sharing
Joint working during transition	Not specified: 9 (69%) Specified: 4 (31%)	
Information to be transferred	Risk assessment and management plan: 6 (46%)	Other: -1 (8%) all case notes -1 (8%) specifically not individual session notes, except where directly relevant e.g. because of high risk levels -1 (8%) nothing specified -2 (15%) 'significant' reports, e.g. Occupational/ Speech & Language Therapy, Psychology -3 (23%) details of interventions & multi-agency working -2 (15%) Framework for the assessment of children in need and their families (DOH, 2000)
Procedures for service users not accepted by AMHS	Nothing mentioned: 10 (77%)	-2(15%) joint discussion between CAHMS and AMHS on further management -1 (8%) find 'alternate' AMHS

Protocols differed in terms of which services/agencies had been involved in developing the protocols; the transition boundary age and whether this was flexible; the procedure for service users not accepted by AMHS; what information should be transferred; and whether the individual's care level according to the Care Programme Approach (CPA) (Department of Health, 1999a) was a transition criterion. Protocols also differed in relation to specifications for the process of transition such as the duration of any transition-planning period and whether a formal transition plan was to be drawn up. Differences in terms of joint working included whether protocols specified a planning meeting between CAMHS and AMHS to help assess need for transition and agree a transition or discharge plan; the involvement of other agencies in this process and CAMHS input post-transition. Although most protocols (n=11, 85%) considered discussion with the service user as central to the transition process, none specified ways of preparing the service user for transition.

Two protocols specifically mentioned a transition liaison worker, one between CAMHS/AMHS and one between adolescent and adult inpatient units. Single protocols (8%) mentioned the local availability of a consultation-liaison service, through which CAMHS could request assessments and advice regarding ongoing care without the need for transition; and the need to conduct an assessment of the carers' needs.

Transition protocols: West Midland sites

Due to small numbers, all protocols in the West Midlands, including draft versions, were subject to content analysis. Two of the three protocols stated the importance of early transition planning and that the decision about which team to involve must be made based on the needs of the service user and the referral criteria of the relevant teams. All three protocols shared similarities with regard to CPA reviews, joint meetings and liaison, and the involvement of service users and their families. All protocols emphasised that transition can occur flexibly over a period of time dependent on individual needs; hence the transfer between the CAMHS and AMHS service should not be based simply on the service user's age (although the protocols all noted changes would be made in order to fall in line with the Children's NSF) and other factors should be taken into consideration, such as the level of maturity, and the nature of the identified need.

The key differences between protocols are summarized in Table 3 below.

Table 3. West Midlands Trust protocol differences

Protocol Theme	N (%)	Further Details
Number of protocols which recorded parties involved in development of the protocol	1 (33%)	A transition steering group was set up consisting of both CAMHS and AMHS members.

Review of transition plan	1 (33%)	1 protocol reviewed after 3 months; other not stated
Transfer of information – permission of service user sought	1 (33%)	Other protocols not stated

2.5 Discussion

In Greater London, in April 2005 there were at least 13 active and two draft transition protocols. In the West Midlands, in October 2007, Coventry and Warwickshire had one active transition protocol, and two others in development. Protocol-sharing CAMHS units varied, from being shared between two trusts, to one trust, several teams within a locality CAMHS and single teams. One CAMHS team had two protocols. Organisational variation therefore does not appear to be a barrier to establishing shared transition protocols. What this study did not and was not designed to answer is whether the variation in protocol-sharing units leaves gaps, i.e. CAMHS/AMHS interfaces that are not covered by agreed protocols, or whether the variation is a result of trying to cover the gaps. Later stages of TRACK will investigate whether the presence of such policies influenced transitions between CAMHS and AMHS and/or continuity of care.

Content analysis of protocols revealed little variation in their underpinning principles, which were based on the National Service Frameworks (Department of Health, 1999b, 2003; Department of Health and Department for Education and Skills, 2004). Protocols did differ on practical aspects of transition, ranging from who was involved with their development to transition boundaries and the process of transition planning, including variations in expected joint working. Three-quarters of the protocols had no provision for ensuring continuity of care for cases not accepted by AMHS. The discrepancy in estimates of numbers per annum thought suitable for transition (0-70) and the numbers that actually make the transition (0-50) raises questions about the outcomes of those who 'graduate' from CAMHS but are not accepted by AMHS, even though a proportion (0-64/several) continue to receive care from CAMHS beyond transition boundaries. The outcome of the rest should be a cause for concern for service providers and commissioners. While it is commendable that CAMHS offers some young people input beyond the transition boundary, this will inevitably have implications for CAMHS caseload, particularly as many CAMHS struggle with long waiting lists. In terms of structural issues (Forbes *et al*, 2002), protocols differed in terms of which services/agencies had been involved in developing the protocols, ranging between two and six, although 5/14 active protocols did not specify who had been involved in the process. General children and young people's policy documents (Department of Health and Department for Education and Skills, 2004; Department of Health, 2006d; Department for Children Schools and Families and

Department of Health, 2008; National CAMHS Review, 2008) and professional good practice guidance on transition and mental health (Lamb *et al*, 2008) advocate multi-agency transition planning and protocol development. Three protocols specifically mentioned a transition liaison worker, two between community CAMHS/AMHS and one between adolescent and adult inpatient units. A single protocol mentioned the local availability of a consultation-liaison service but none mentioned a transitional service, although 16 respondents described themselves as 'adolescent' teams/services.

All protocols considered an 'enduring mental health problem' as an important criterion for referral to AMHS. The term 'enduring mental health problem' seems to be a hybrid of the term 'severe and enduring mental illness', used by adult services, and 'mental health problems', a term used more in CAMHS. Stakeholders in the transition process may well hold differing conceptions of mental health, mental illness or disorder/problems (Sroufe, 1990; Gillett, 1999; Kendell and Jablensky, 2003). Young people with mental health problems as understood in a developmental or CAMHS context may not fulfil the disorder/illness criteria used by AMHS for prioritising and targeting mental health care. So, while individuals with psychosis or severe mood disorder may have their care suitably transferred, others with conduct disorder, ADHD, borderline learning disability, autism spectrum disorder, etc., may fall through the care net if not considered suitable for AMHS. Stage 2 of TRACK will address this issue further.

In terms of the policy imperatives that Care Programme Approach be used in making transition decisions (Department of Health, 1999a; Department of Health and Department for Education and Skills, 2004), only 3/13 (23%) of protocols in Greater London required use of the CPA. Within these protocols, CPA levels were used to distinguish between young people considered 'appropriate for AMHS' (service users on Enhanced CPA) and those who would 'be considered' appropriate for AMHS (on Standard CPA). It is possible that such a dichotomy allows AMHS to restrict its involvement to those with a 'severe and enduring mental illness' and to 'consider' those with an 'enduring mental illness'. In the West Midlands, by October 2007, all three protocols stipulated the use of CPA reviews at transition.

Most protocols identified the service user as central to the transition process. This is in keeping with policy documents such as the Department of Health document *Transition: getting it right for young people* (2006d), good practice guide (*Transition: moving on well*, Department for Children Schools and Families and Department of Health, 2008) and the Children's NSF Core Standard 4: 'Growing up into Adulthood' (Department of Health and Department for Education and Skills, 2004). All these policy documents stress the need to involve service users and carers in the transition process and decision making and prepare them for transition. However, none of the protocols included in this study specified ways of preparing service users or carers for transition. This suggests that protocols are being written more with policy than clinical practice in mind.

Protocols also differed in the process of transition such as the duration of any transition-planning period, whether there needed to be a joint planning meeting between CAMHS and AMHS, and whether a formal transition plan was to be drawn up or CAMHS involved post-transfer.

When should the mental health problems of a young person looked after by CAMHS become the responsibility of AMHS? Our data showed that age-based transition boundaries varied between 16 years to 21 years and over, with 18 being the mode. There is clearly no consensus on this issue although national policy will soon require comprehensive CAMHS to be provided for young people until the age of 18 years (Department of Health and Department for Education and Skills, 2004). Current boundaries are based on historical service development reasons rather than evidence or best practice. The variation in boundary definition depending upon educational or employment status is difficult to justify. If adult services are appropriate for unemployed 16-year-olds who are still living with their parents, why are adult services not appropriate for 17-year-olds who are about to leave the sixth form for university? The majority of protocols we collected did mention the need for flexibility when applying age-based transition criteria. However, there seems little consensus either on how such flexibility can be mutually agreed between services or operationalised in protocols. Mental health services for 16- and 17-year-olds are disproportionately expensive – so that comprehensive mental health services for individuals up to their 18th birthday may cost around twice as much as similar services that end at people's 16th birthday (Goodman, 2005). If cost is the reason behind a service gap for 16- to 18-year-olds, then the only way to bridge this gap is to resource services adequately.

Some argue that the best way forward is to develop specialist youth health services (Viner and Barker, 2005). YoungMinds have produced examples of good practice and guidance for commissioners in relation to services for 16-25 year olds (YoungMinds, 2006a, b). Our findings suggest that the complexity of service structures, arbitrary service boundaries, variation in protocols and possible policy-practice gap all contribute to such a discontinuity of mental health care for a significant number of young people who experience no or poor transition of care across services.

Main limitations

At the time of our data collection in Greater London, a comprehensive map of CAMHS services was unavailable. We identified services using information from several sources. Our aim was not to map CAMHS provision but to identify existing transition protocols. Responding teams in our study varied from generic to targeted and inpatient teams, and from locality-based to wider and national teams. While our study may not have captured responses from every relevant CAMHS and hence some selection bias is inevitable, the wide variation in responding teams suggests that the findings are representative of transition issues facing CAMHS in Greater London. Greater London is primarily urban and changes in service delivery are also frequently initiated in the capital. Both these factors may also limit the generalisability of our findings to other parts of the country. Nonetheless,

when including West Midlands sites, we utilised the appropriate CAMHS Mapping Atlases (Department of Health, 2006b) and covered a more diverse geographical area, including services covering rural, semi-rural and non-London urban areas.

Mapping data from London sites was already available at the beginning of the SDO-funded part of the project (Singh *et al*, 2008). However, completing Stage 1 in the West Midland sites was challenging, with several unexpected difficulties including procedural delays and poor participation from clinicians. Despite having site specific assessment (SSA) exemption and Multi-centre Research Ethics Committee (MREC) approval for the study, one local trust questioned the earlier decisions of the MREC and asked for repeated clarifications, both from the study team and the MREC. This led to considerable delay in commencing the study in West Midlands. Although all documentation was provided to the local R&D committee's satisfaction by August 2006, there was further delay in getting R&D approval due to trust reorganisation (mental health services within three participating trusts were reorganised under one trust). The approval, received in February 2007, was later retracted by the committee due to further concerns raised by the head of one of the CAMHS. The concerns were not shared by the MREC but final approval was delayed until March 2007. This procedural delay hindered Stage 1 significantly and resulted in lower recruitment, given the timeframe of the study.

At the time of data collection in Coventry and Warwickshire, there were three relevant trusts, whose mental health services have since amalgamated into one trust. Although this did not affect mapping process, it did have implications for later stages of TRACK. Additionally, despite stated enthusiasm for the study, Birmingham and Solihull clinician response rates were so poor and the quality of information in the few returns so incomplete that these sites had to be dropped from TRACK. This limited the richness and diversity of data collected from sites outside London.

Finally, the presence of a protocol does not necessarily ensure that actual practice adheres to stated policy. Stage 2 of the TRACK project aimed to identify any such policy-practice gaps.

3 Stage 2: Case note survey of transitions

'...I do feel a bit like when our young people hit eighteen we just have to say to them "that's it, that's your lot" because we just know that they're not going to meet the threshold for an adult service. And I have done that recently, I didn't bother to refer because I just knew she wouldn't qualify for the service.' – CAMHS key-worker

'...the problem with the adult transferral services is that we actually find it nearly impossible to transfer anything else except psychosis – it's complicated when you have anything combined with depression, it's really impossible to transfer...' – Psychiatrist, CAMHS

3.1 Aims

The aim of Stage 2 was to evaluate the process of transition using a case note survey, to identify all actual and potential referrals from CAMHS to adult services in the preceding year, to 'track' their progression through the service boundaries and evaluate their outcomes in terms of referral process and engagement with adult services, and thereby determine predictors of achieving transition. Throughout the section, the term 'cases,' rather than young people or service users, will be used. This is because we consulted case notes rather than the young people themselves; views of service users will be addressed in Stage 4 (section 5).

3.1.1 Definitions

We defined **actual referrals** as anyone who was referred to, and accepted by, an adult mental health service (AMHS) from a child and adolescent mental health service (CAMHS). **Potential referrals** included anyone who crossed the transition boundary during the study period but did not make a transition to adult care because

despite being considered to have an ongoing mental health need they were **not referred** to AMHS due to a lack of an appropriate service, the client refusing referral, etc.

they were **still being seen** by CAMHS.

they were **not accepted by** AMHS.

Transitions were also evaluated according to whether they were considered to be 'optimal' or 'suboptimal'. Freeman *et al's* (2000) elements of continuity are given in brackets.

Optimal transition was defined as meeting the following criteria:

Continuity of care - either engaged with AMHS three months post-transition or appropriately discharged;

and the following three further variables (explored below in further detail):

Period of parallel care (relational continuity), i.e. a period of joint working where the service user is involved with both CAMHS and AMHS;

Transition planning meetings (cross-boundary and team continuity), i.e. at least one meeting discussing the transition from CAMHS to AMHS, involving the service user and/or carer and key professionals, prior to the handover of care from CAMHS to AMHS;

Optimal information transfer (information continuity), i.e. any or all of the following transferred from CAMHS to AMHS:

referral letter
 summary of CAMHS contact
 any or all CAMHS notes and a contemporary risk assessment

Suboptimal transitions were those that failed to meet one or more of the above criteria.

3.2 Method/design

A pilot survey of clinicians in South and East London had suggested that the rate of transition from CAMHS services to adult care is about 20 per million population per year, with another 10-15 per million per year being potential referrals. At this rate, within the study area, we expected 70-80 service users to make a transition each year (actual referrals) and 35-50 potential referrals.

For CAMHS teams to be included in the study, they had to meet the following criteria:

- be defined as tier 2, tier 2-3 or tier 3 CAMHS;
- manage young people up until the age of transition; and
- refer cases to Adult Mental Health Services (AMHS).

CAMHS tier 4 inpatient units were included only if they managed young people up until the age of transition, while other highly specialised (tier 4 or tertiary) outpatient services were excluded because they dealt with extremely atypical populations of young people and accepted referrals from all over the country providing practical obstacles to tracking.

3.3 Data collection tools

3.3.1 Case ascertainment

In order to identify CAMHS teams that met the inclusion criteria the local collaborators for each site were asked to identify services and set up face to face meetings with the lead clinician for each, who, in turn, were also asked to identify suitable teams.

Within each included team, actual and potential referrals were identified from the preceding year using a two-stage process:

Phase 1: central databases searches

Phase 2: asking individual clinicians within teams to identify actual and potential referrals in the preceding year.

The exact dates for the preceding year differed for each trust due to data being collected at different time periods, but the data were collected from all sites for a 12 month period between 2005 and 2007. Data collection began in Trust L1 in April 2005, L2 in November 2006, L3 in December 2006, and the West Midlands Region Trusts in February 2007.

3.3.2 Phase 1: accessing databases

CAMHS databases

The central CAMHS databases for all trusts were accessed via IT teams using appropriate local data extraction procedures to obtain a list of:

- all young people whose cases were open when they reached aged X
(where X is the last chronological year of age for which they should be seen by CAMHS as defined in the local transition arrangements), and to identify how many

- were considered for transfer to adult services

- were expected to have on-going needs

- any young people aged X+1 or older whose cases were open to CAMHS, in order to check how many were still being seen because of the lack of an adequate adult service

AMHS databases

The central AMHS databases for all trusts were similarly accessed to obtain a list of:

- all young people aged below the lower age cut-off on AMHS referral criteria, who had been referred to AMHS, and to identify
 - by whom,
 - whether they were accepted, and
 - why they were not referred to CAMHS (if the referrer was not CAMHS)

- all service users referred by CAMHS regardless of age

- all young people aged between the lower age cut-off on AMHS referral criteria and their 19th birthday, who were referred by non-CAMHS referrers, in order to cross-reference with CAMHS records to:

- identify whether any of them had been open to CAMHS in the preceding year

- check why CAMHS had not referred them

3.3.3 Phase 2: contacting clinicians

All CAMHS clinicians were asked for a list of all actual and potential referrals from their service to AMHS during the same year as in Phase 1 for that trust. Identified cases were cross-checked with the above database lists. Any discrepancies were raised with clinicians and/or heads of service and discussed to ascertain relevance to the project.

3.3.4 Developing the TRACKING tool

The TRACK questionnaires used to extract case note data were devised, piloted and reviewed by members of the TRACK team including CAMHS and AMHS psychiatrists. Separate questionnaires were used for actual (see *Appendix 2* for Actual Questionnaire) and potential referrals (see *Appendix 3* for Potential Questionnaire). Reviewed data were recorded in categorical, script and numerical form.

3.3.5 Data collection

The case notes of all cases thus identified as actual or potential referrals were subjected to a retrospective case note review. Researchers used the TRACK questionnaires to extract data from case notes at the relevant CAMHS team base. In the case of actual referrals, data were also extracted from the AMHS notes at the AMHS team base.

For actual referrals the following information was collected:

Clinical and socio-demographic details, including presenting problem at time of transition

Time from referral to assessment

Outcome of referral (accepted by adult services or not)

Time from referral to acceptance

Documented hand-over planning

Quality of information transfer (information continuity)

Nature and frequency of joint working during transition (therapeutic, relational and cross boundary continuity)

Any problems or difficulties documented during transition

Contact frequency, types of contacts and contact by whom

Admissions, discharges, referrals to other services

In order to access service users for Stage 4 interviews, researchers also collected information on last known address/phone number; last known GP details, and current case manager/key-worker (i.e. name, role, service contact details).

Due to the variation in case note descriptions of service users' presenting problems and diagnoses at the time of transition, it was deemed necessary to categorise presenting problems into distinct diagnostic groups for the purposes of data analysis. The following seven categories were agreed by CAMHS and AMHS clinicians in the study steering group:

Serious and enduring mental disorders: including schizophrenia, psychotic disorders, bipolar affective disorder, depression with psychosis

Emotional/neurotic disorders: including anxiety, depression (without psychosis), post-traumatic stress disorder, obsessive-compulsive disorder

Eating disorders: Anorexia Nervosa, Bulimia Nervosa, atypical eating disorder

Conduct disorders: including conduct disorder, behavioural disorder

Neurodevelopmental disorders: including Asperger syndrome, autism spectrum disorder, learning disabilities

Substance misuse disorders: alcohol and/or drug misuse

Emerging personality disorder

For potential referrals, additional information was collected on:

Current status (ongoing care by CAMHS, current management plan, discharged to GP, lost to follow up or other)

Factors accounting for the decision not to refer to adult services.

3.4 Statistical analysis

3.4.1 Reliability of data extraction

A reliability study was conducted by two researchers who independently collected data from five actual referrals from a site unrelated to the project using the study tools. These data were subjected to a data validation analysis by comparing the two resulting databases using validation software. For each of the five cases 491 non-text variables were completed and compared. Inconsistencies between databases were identified and where inconsistencies were related to coding of 'missing' or 'not applicable' variables or differences in number of decimal places used these were ignored. An error rate less than 2% resulted and was deemed to be satisfactory.

3.4.2 Transition pathways

Descriptive statistics and graphical presentation were used to examine transition pathways of all cases. Numbers and percentages of cases experiencing different pathways were determined and sub-analyses conducted by study region and included trusts.

3.4.3 Predictors of achieving transition

The modelling strategy used in this analysis uses an exploratory approach. Given the lack of evidence in the area it was not possible to construct hypotheses to test the effect of hypothesised predictor variables. A two stage analysis was therefore conducted. The first stage identified which

independent variables had at least a weak association ($p < 0.1$) with the dependent variable. Variables found to have such a univariate association were then entered into logistic regression. Variables were entered simultaneously, without *a priori* assumptions about which variables were more influential than others. The results of the logistic regression were interpreted in terms of those independent variables found to be significant at the 5% level, $p < 0.05$.

The dependent variable in this analysis was whether referrals are 'actual' or 'potential'. The independent variables were drawn from four groups:

demographics: gender, age at first referral to CAMHS, ethnicity (i.e. Asian, Black, White, Mixed/Other, or not recorded), first language, accommodation (i.e. parents' home, on own, or other), highest education status reached, whether currently in education or employment, parental status (i.e. married or cohabiting, other, or not recorded), family history of mental health difficulties (i.e. any record in CAMHS or AMHS case notes of mental health difficulties in parents, siblings, uncles/aunts, grandparents or other family);

indicators of broader social risks while attending CAMHS: Looked After Child (LAC) at any point, special educational needs, Child Protection involvement, Youth offending Team (YOT) involvement, a refugee or asylum seeker;

service use: parental attendance at CAMHS (i.e. regularly – attending more than 50% of appointments, sometimes – attending less than 50% of appointments, or never – no evidence of ever attending any appointments), type of referral to CAMHS (i.e. routine or urgent), discipline of key-worker at time of transition;

clinical variables: any periods of mental health inpatient care, any MHA detentions under CAMHS, presenting problem, comorbidities (i.e. presenting problems at the time of leaving CAMHS fitting into more than one of the following categories: serious and enduring, emotional/neurotic, eating disorder, conduct disorder, neurodevelopmental disorder, substance misuse, or emerging personality disorder).

Reliability of data coding

Two CAMHS psychiatrists independently categorised presenting problems using the above definitions, and a third psychiatrist independently resolved any discrepancies arising in categorisations. There was a high level of agreement (95%) between the two independent psychiatrists, with only eight cases needing to be resolved by the third. Young people who

presented with problems that fell into more than one of the categories described above were allocated to more than one group and described as having a 'comorbid' presentation.

Tests for univariate association

Each variable was tested for univariate association with achieving 'actual' or potential' referral status (dependent variable) using Pearson χ^2 tests (Fishers exact tests where necessary) for categorical variables and unpaired t-test for the continuous variables. Those variables found to be significantly associated at the 10% level (i.e. $p < 0.1$) with the dependent variable were taken into the second stage of analysis.

Tests for co-linearity of independent variables

In the second stage of analysis, variables found to have a univariate association with the dependent variable were to be entered in a logistic regression. Prior to the logistic regression, however, it was necessary to examine whether any of the independent variables were highly associated with each other (co-linear) at a 5% significance level (i.e. $p < 0.05$). Those independent variables found to be highly associated with each other were either recoded to create composite variables or one dropped (where it was felt one variable was more clinically relevant than another).

Logistic regression

Variables identified as relevant in the univariate analysis were entered into a logistic regression model to explore their relationship with the dependent variable. The 'Enter' selection method was used to enter independent variables into the logistic regression. The results of the logistic regression model are presented using odds ratios and 95% confidence intervals. Results of the logistic regression are interpreted by examination of those variables which are significant at the 5% level (i.e. $p < 0.05$).

3.4.4 Predictors of achieving an optimal transition

This analysis was carried out as in section 3.4.3 but the dependent variable in this case was whether a service user achieved continuity of care (definition: either engaged with AMHS at three months post-transition or appropriately discharged) or not. This analysis was only carried out on those who had made a transition to AMHS.

3.5 Results

3.5.1 Case ascertainment

Efforts to use databases to find cases were unsuccessful because of the poor quality of the datasets (see section 3.5.1 *Difficulties with Phase 1 Case Ascertainment* below). In London sites, a total of 113 cases and in the West Midlands sites a total of 42 cases were tracked completely, i.e. both CAMHS and AMHS notes were viewed for actual referrals and CAMHS notes were

viewed for potential referrals. Eleven cases (9 in London and 2 in the West Midlands) were partially tracked, i.e. these cases were actual referrals but only the CAMHS notes were viewed. Another 20 cases were identified as suitable for inclusion (18 in London and 2 in the West Midlands) but could not be included due to time restrictions. Table 4 details the number of cases tracked in each borough/locality for each site. Nine CAMHS Teams in London reported that they had no relevant cases.

Using this retrospective case note survey method, the rate of actual and potential referrals per 100,000 population (Office for National Statistics, 2002) in the London sites were 2.68 and 1.49 respectively, very close to the figures estimated in the initial pilot. The rate of actual and potential referrals per 100,000 population in the West Midlands sites were 2.23 and 2.97 respectively.

Table 4. Cases tracked by borough/locality

Borough/ Locality	Complete: CAMHS and AMHS (where relevant) case notes tracked			Half-complete: (CAMHS notes tracked)	Not viewed (files identified as relevant but not viewed)
	Actual	Potential	Totals	Actual	
L1	22	5	27	0	0
L2	27	23	50	0	10
L3	23	13	36	9	8
sub-totals	72	41	113	9	18
WM1	3	2	5	0	0
WM2	2	4	6	0	2
WM3	13	18	31	2	0
sub-totals	18	24	42	2	2
Totals	90	65	155	11	20

Difficulties with phase 1 case ascertainment

In the West Midlands Trusts included in the study, there were no inpatient (tier 4) units. Tier 4 provision is somewhat complex and, on behalf of 17 PCT's, the West Midlands Specialised Services Agency (WMSSA) is responsible for commissioning all CAMHS tier 4 services for children and young people under 18 years of age. Due to the unforeseen delay in receiving local R&D approval (see section 2.5 *Main Limitations*), it was decided that cases from the included West Midlands trusts who had been admitted to tier 4 units outside the participating trusts would not be included. Similarly, in L2 there were a number of tier 4 national and specialist services. Again due to the difficulties inherent in following up

national cases, such as getting R&D approvals from non-participating trusts, it was decided that these services would not be included in the study.

Difficulties were encountered when searching the central CAMHS databases in London. In London Trust 1, the list obtained was of no practical utility, being vast and including every person ever seen by CAMHS services from the appropriate year of birth. In London Trusts 2 and 3, the databases could not be searched according to the study criteria and reports were produced based on age and status criteria only. As these lists were of restricted usefulness, enquiries were made into searching databases at the borough level for London Trust 2. This proved futile as two out of the four boroughs had no suitable databases during the study period, and two had databases that could not be searched according to the study criteria.

In the West Midlands trusts there was no central database. However, one of the localities, WM3, did have a PAS database which was searched and a report was produced based on age only. The report identified all CAMHS cases who reached the transition boundary (i.e. 17+) between 01/01/2006 and 31/12/2006, which were either closed in 2006 or continued to be seen by CAMHS.

In order to search adult databases, the IT services in each trust were contacted. Useful lists were obtained in London Trusts 1 and 2 and WM locality 2. London Trust 3 and West Midlands localities 1 and 3 had no central database so individual team databases were searched, with some producing useful lists.

Overall we encountered several problems in case ascertainment via central datasets including lack of suitable databases; databases could not be searched according to proposed criteria; delays in gaining access to databases; and varying comprehensibility and accuracy in the reports produced by the databases. Thus, the database search was abandoned in favour of asking individual clinicians to identify cases (Phase 2).

Difficulties with phase 2 case ascertainment

In this phase we tried to ask individual clinicians within relevant teams to identify actual and potential referrals in the preceding year. Problems in Phase 2 included clinicians unwilling to meet study team because of busy clinical schedules and high staff turnover whereby relevant clinicians had left the service during the study period. Some clinicians commented that their high caseload would lead to a difficulty in remembering all relevant cases.

3.5.2 Transition pathways

Of the 155 cases tracked, 90 (58%) were accepted by AMHS (i.e. actual referrals). Sixty-four (42%) were potential referrals, i.e. those who crossed the transition boundary during the study period but did not make a transition to adult care. One case was excluded from subsequent analysis as it was found that this case was not referred on to an adult mental health service but a neurologist. Case notes of all actual and potential referrals

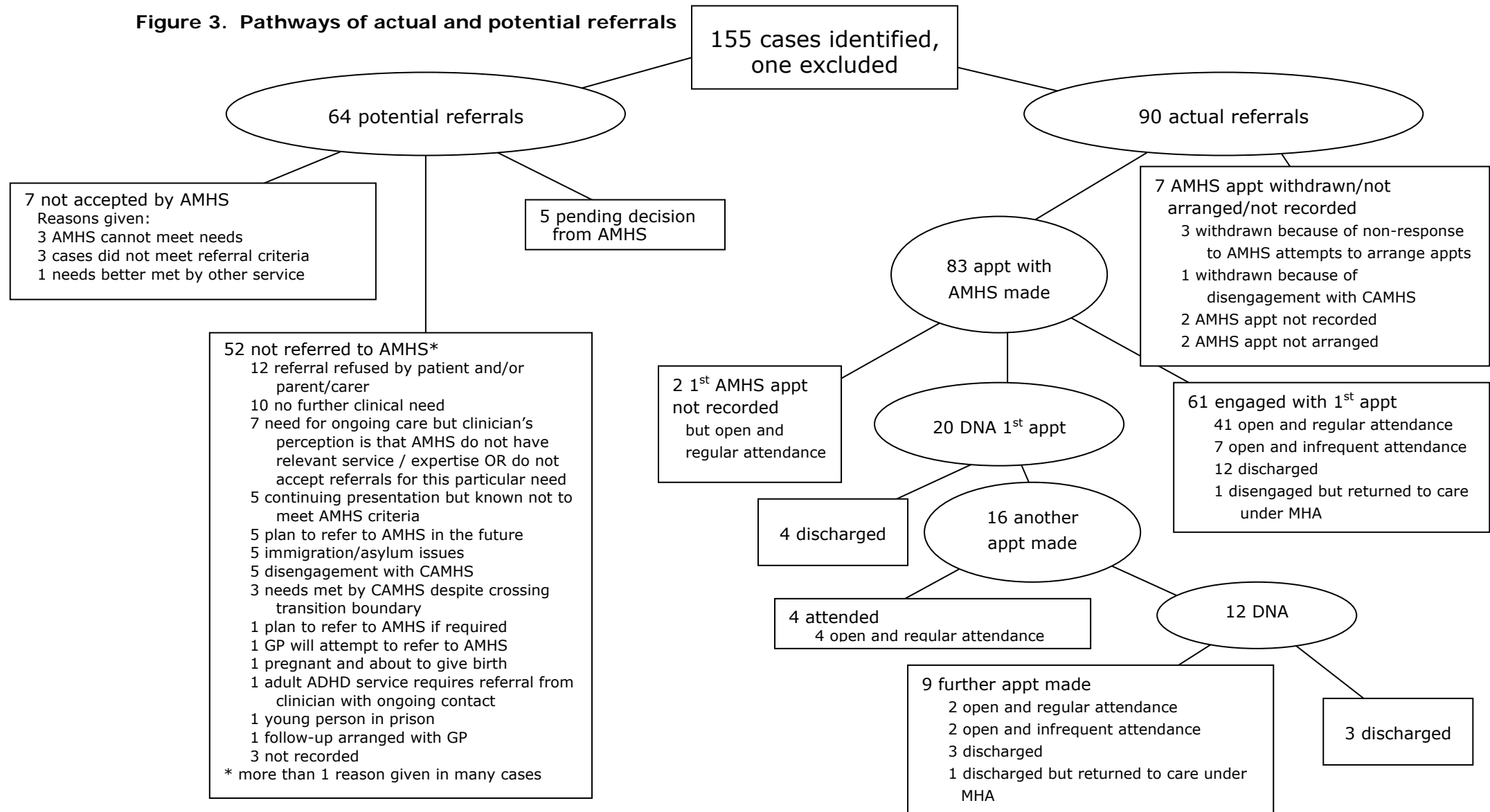
were tracked up to attendance at and/or discharges from AMHS (in the actual referral cases) or non-acceptance / reasons for non-referral (in the potential referral cases). Figure 3 illustrates this information. The subsequent analysis is on a total of 154 cases.

One hundred and thirty-one of the 154 (85.1%) young people reaching the transition boundary between CAMHS and AMHS were thought suitable for transition by CAMHS clinicians. Of the 131, in 12 (9.2%) cases the young person and/or a parent/carers refused referral to AMHS (1 refusal by parent/carers only, 2 by the young person and parent/carers and 9 by the young person only), in another 12 (9.2%) referrals had not been made because CAMHS thought AMHS would not accept the referral or because they did not think AMHS had appropriate services. In five cases (3.8%) referral to AMHS was planned but had not been made. Only 102/131 referrals to AMHS were made, i.e. 77.9% of those cases thought suitable for transition. Of these, 90 (88.2%) had been accepted by the end of data collection, with five (4.9%) still pending a decision by AMHS. Only seven (6.9%) had been refused by AMHS, either because they did not meet AMHS criteria (3/102, 2.9%) or because no suitable service was available (3/102, 2.9%) or because an alternative service was thought to be suitable (1/102, 0.9%).

Of the 90 cases referred to and accepted by AMHS, 58 (64%) remained open to follow up by AMHS. Twenty-six percent (23/90) were discharged following attendance at AMHS or following failed appointments. Twenty-four percent (20/83) of cases missed their first appointment. Seven cases (7.8%) were referred but had their first appointment withdrawn, had no appointment recorded or no appointment arranged.

Almost a quarter failed to attend the first appointment offered by AMHS (20/90), of whom four fifths were offered a second appointment, only a quarter of which were attended. All the rest were offered a second appointment, of which only a quarter were attended. All those who did not attend the second appointment nine (75%) were offered a third appointment, of which about half were attended. About a quarter were discharged following attendance at AMHS or following failed appointments. Only two thirds of the actual referrals remained open to AMHS when surveyed (64.4%). Sixteen cases (18%) were discharged without being seen.

The length of any wait to be seen by AMHS has not been recorded in the case note data so this information is not available. However, the number of appointments offered in the first three months has been recorded, and out of the 90 actual referrals, five cases (5.5%) did not have an appointment in the first 3 months. Seven cases (7.8%) had only one appointment.

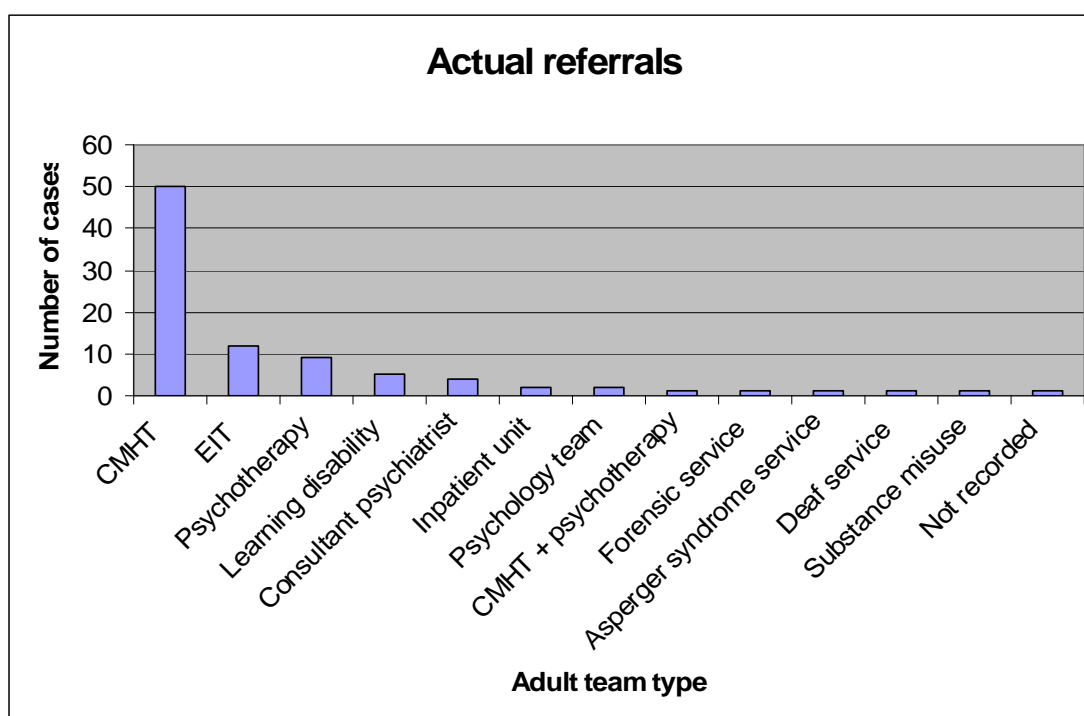
Figure 3. Pathways of actual and potential referrals

Transition pathways from different CAMHS to different adult teams

Of the 90 cases accepted by AMHS (i.e. actual referrals), 56 (36.4%) were from adolescent units (all in London). The transition boundaries for the adolescent teams were 18 years in all cases, with some flexibility in 5/6 units. The transition boundaries for the child and adolescent teams were 18 years for all London teams and 17 for all West Midlands site teams, although there was stated flexibility in the protocols.

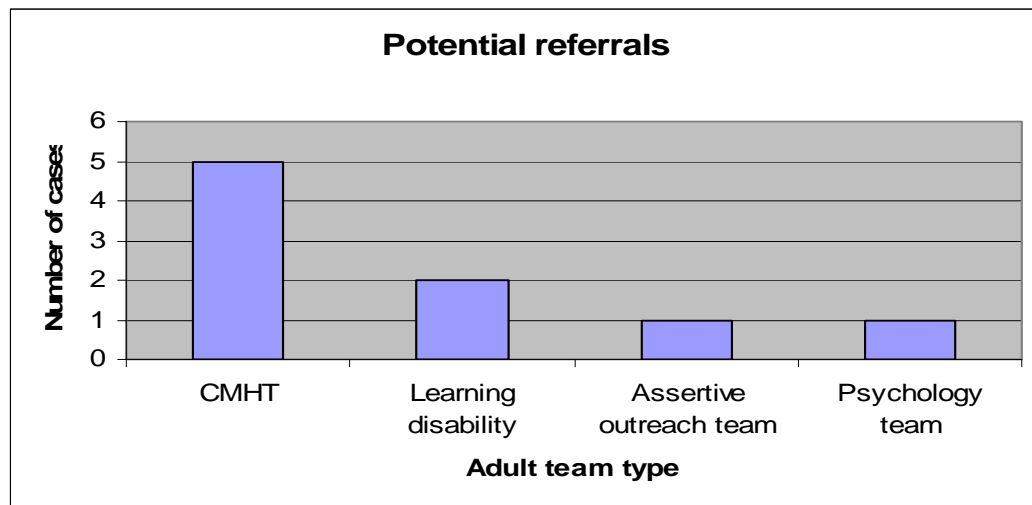
Of the 90 cases accepted by AMHS (i.e. actual referrals), CAMHS made referrals to the following: 50 referrals to Community Mental Health Teams (CMHTs), 12 to Early Intervention Teams (EITs), 9 to adult psychotherapy services, 5 to learning disability services, 4 to consultant psychiatrists, 2 to adult inpatient units, 2 to psychology teams and one each to a CMHT/adult psychotherapy service, forensic service, Asperger syndrome service, deaf service, and substance misuse team (Figure 4). One referral target was not recorded in the notes.

Figure 4. AMHS team destinations for CAMHS referrals accepted by AMHS



Stage 2 case notes indicated the following destinations for unsuccessful referrals from CAMHS to AMHS (potential cases): 5 to CMHTs, 2 to learning disability services and one each to an assertive outreach team and a psychology team (see Figure 5). No unsuccessful referrals were made to Early Intervention Teams. There was therefore no clear pattern suggesting that some specific adult service types did not accept CAMHS referrals although EI services appear to accept all referrals from CAMHS.

Figure 5. AMHS team destinations for CAMHS referrals not accepted by AMHS



Reasons why potential referrals were not actual referrals

The commonest reason for potential referrals not to be referred was that CAMHS clinicians did not expect the referral to be accepted by AMHS or that AMHS did not accept the referral (n=16) (see Figure 3). Other reasons included the referral being refused by the service user and, in some instances, the parent/carer (n=12) or there being no further clinical need (n=12). The characteristics of these three groups were examined further and some striking differences were revealed.

In the group where there was an ongoing clinical need but the service user was not referred on to AMHS because the clinician did not expect the referral to be accepted, or where AMHS did not accept the referral, the majority of service users were based in Trust L2 (n=11), with others in WM Trust (n=3), L1 (n=1), and L3 (n=1). The group consisted of nine females and seven males and ethnicity was White (n=8), Black (n=4), not recorded (n=2), Asian (n=1), and Mixed/Other (n=1). The mean age of first referral to CAMHS was 13.31 years. The majority of cases fell into either neurodevelopmental disorders (n=6, 37%) or emotional/neurotic disorders (n=5, 31%), and one case fell into both these categories. The other three cases were divided between serious and enduring mental illness (n=1), eating disorders (n=1) and substance misuse (n=1) categories. Four service users had at least one parent who attended CAMHS regularly, none had been admitted to hospital due to mental health problems, and seven were on medication at the time of crossing the transition boundary.

In the group where the referral was refused by the service user and/or carer, all of the cases were based in London, with L3 having half the cases (n=6) followed by L2 (n=4) and L1 (n=2). The group was divided evenly between males and females, and ethnicity was mixed between White (n=4), Black (n=3), Asian (n=2), not recorded (n=2) and Mixed/Other (n=1). The mean age at first referral to CAMHS was 14.42 years. A third fell into the emotional/neurotic diagnostic category (n=8), followed by

neurodevelopmental disorders (n=2), neurodevelopmental disorder and substance misuse (n=1), and serious and enduring mental illness (n=1). Three service users had at least one parent who attended CAMHS regularly, and nine service users were on medication at the time of crossing the transition boundary. Two service users had been admitted to hospital due to mental health problems, one of these under the MHA.

In the group that were not referred on to AMHS as there was no further clinical need, the vast majority of service users were based in WM Trust (n=11) and only one was based in London (Trust L2). The group was divided evenly between males and females, and ethnicity was not recorded in most cases; the others were White (n=3) and Black (n=1). The mean age at first referral to CAMHS was 14.58 years. Half of the cases fell into the emotional/neurotic diagnostic category at the time of crossing the transition boundary (n=6, 50%), followed by eating disorders (n=3, 25%), neurodevelopmental disorders (n=2, 16%) and conduct disorder (n=1, 8%). Five young people had at least one parent who attended CAMHS regularly, none had been admitted to hospital due to mental health problems at any time, and three were on medication at the time of crossing the transition boundary.

3.5.3 Sample description

The total sample (both actual and potential referrals) consisted of 78 (51%) males and 76 females, with a mean age of 18.12 (SD 0.824) at the time of data collection. The majority ethnic group was White (31%), followed by Black (23%), although no ethnicity was recorded for a large portion of the sample (27%). The majority (76%) spoke English as their first language. Most of the young people in the sample lived with their parents (71%) and were either in employment or education (60%).

Most young people's presenting problem at the time of transition fell into the diagnostic category of emotional/neurotic disorders (n=78, 51%), followed by neurodevelopmental disorders (n=38, 25%) and serious and enduring mental disorders (n=34, 22%). Much less frequently presenting problems fell into the categories of substance misuse (n=14, 9%), conduct disorders (n=6, 4%), eating disorders (n=6, 4%), and emerging personality disorder (n=4, 3%). In five cases (3%) the presenting problem was not recorded. Total percentages add up to more than 100% here as almost a fifth of young people (n=29, 18.8%) had more than one presenting problem at time of transition, i.e. they fitted into more than one diagnostic category.

Most of the co-morbid cases fitted into two categories (n=27). Of these, 21 were actual referrals and six were potential referrals. Two cases fitted into three categories (serious and enduring mental illness, neurodevelopmental disorder and substance misuse; conduct disorder, neurodevelopmental disorder and substance misuse) and were both actual referrals, but only one had received ongoing care from AMHS. The most common comorbid categories were emotional/neurotic disorders and neurodevelopmental disorders (n=7), of which five were actual referrals and two received ongoing care. The next most common comorbid categories were serious and

enduring mental illness and substance misuse (n=6), of which all were actual referrals and four were receiving ongoing care from AMHS.

3.5.4 Predictors of achieving transition

Trusts

Table 5 below illustrates the number of actual and potential referrals by trust. Trust L2 had the highest number of actual referrals (n=26) and Trust WM had the lowest (n=18). Trust WM had the highest number of potential referrals (n=24) and Trust L1 the lowest (n=4).

Table 5. Actual and potential referrals by trust

Team Trust	Actual referrals (n=90)		Potential referrals (n=64)	
	n	%	n	%
L1	23	85%	4	15%
L2	26	53%	23	47%
L3	23	64%	13	36%
WM	18	43%	24	57%
Totals	90	58%	64	42%

The percentage of actual referrals differed significantly between the trusts ($\chi^2=13.175$, $p=0.004$) with WM Trust having the lowest percentage of actual referrals to AMHS, only 43%, and L1 having the highest percentage at 85%. However, upon closer examination, it was found that Trust L1 had the highest percentage of cases with serious and enduring mental illnesses (37%), while WM Trust had the lowest (5%), $\chi^2=11.576$, $p=0.009$.

Trust L1 had the highest ratio of actual to potential referrals (5.75:1) and Trust WM the least (0.75:1).

Table 6. Actual and potential referral ratios by trust

Team Trust	Actual referrals (n=90)		Potential referrals (n=64)		Actual: Potential ratio	Totals (n=154)	
	n	%	n	%		n	%
L1	23	25.6%	4	6.3%	5.75:1	27	17.5%
L2	26	28.9%	23	35.9%	1.14:1	49	31.8%
L3	23	25.6%	13	20.3%	1.77:1	36	23.4%
WM	18	20.0%	24	37.5%	0.75:1	42	27.3%

Teams

Referrals from CAMHS specifically for an adolescent age group (as opposed to CAMHS which managed both children and young people) were not more likely to achieve transition. On the AMHS side, referral to Early Intervention

in Psychosis Teams or CMHTs were significantly associated with achieving transition ($p < .0001$) although numbers referred to other types of AMHS were relatively low. In our sample, referral to an Early Intervention service always resulted in transition.

Demographic variables

There were no differences between the actual or potential referrals in terms of the following demographic variables; gender, age at first presentation to CAMHS, ethnicity, first language spoken, educational or employment history, parental status, having special educational needs, Youth Offending Team involvement, refugee or asylum seeker status. However, the actual referrals were significantly more likely to be living on their own, to have a family history of mental health difficulties, to have been a Looked After Child or to have had Child Protection involvement while attending CAMHS (using a 10% significance level). Only living on their own, Looked After Child status and evidence of Child Protection involvement were significant at a 5% level.

Table 7 illustrates demographic variable comparisons between actual and potential referrals.

Table 7. Demographic variables comparing actual and potential referrals

	Actual referrals n (%)	Potential referrals n (%)	Total n (%)	Chi-Square	<i>p</i> value
<u>Gender</u>					
Male	49 (54.4)	29 (45.3)	78 (50.6)	1.248	0.26
<u>Age at first referral to any CAMHS</u>					
Mean	13.34 (n=88)	14.29 (n=63)	13.74 (n=151)	t=-1.696	0.09
Std Dev.	3.907	2.937	3.555		
<u>Ethnicity</u>					
Asian	8 (8.9)	5 (7.8)	13 (8.4)	4.531	0.34
Black	23 (25.6)	13 (20.3)	36 (23.4)		
Mixed/Other	13 (14.4)	4 (6.3)	17 (11.0)		
White	26 (28.9)	21 (32.8)	47 (30.5)		
NR (not recorded)	20 (22.2)	21 (32.8)	41 (26.6)		
<u>Language</u>					
English as first language / NR	82 (91.1)	54 (84.4)	136 (88.3)	1.64	0.200
First language other	8 (8.9)	10 (15.6)	18 (11.7)		
<u>Accommodation</u>					
Parent(s)' home	58 (64.4)	52 (81.3)	110 (71.4)	6.997	0.03

On own	13 (14.4)	2 (3.1)	15 (9.7)		
Other	19 (21.1)	10 (15.6)	29 (18.8)		
<u>Highest education reached to date</u>					
GCSEs and below	43 (47.8)	27 (42.2)	70 (45.5)	1.35	0.51
above GCSEs	36 (40.0)	24 (37.5)	60 (39.0)		
NR	11 (12.2)	13 (20.3)	24 (15.6)		
<u>Evidence that young person is in education and/or employment</u>					
Yes	58 (64.4)	35 (54.7)	93 (60.4)	1.489	0.22
No/NR	32 (35.6)	29 (45.3)	61 (39.6)		
<u>Parental status</u>					
Married/ cohabiting	25 (27.8)	22 (34.4)	47 (30.5)	1.242	0.74
Separated/ divorced	44 (48.9)	31 (48.4)	75 (48.7)		
1 or 2 parents deceased	14 (15.6)	7 (10.9)	21 (13.6)		
Other/NR	7 (7.8)	4 (6.3)	11 (7.1)		
<u>Family history of mental health difficulties</u>					
Yes	51 (56.7)	22 (34.4)	73 (47.4)	3.644	0.06
No	15 (16.7)	15 (23.4)	30 (19.5)		
NR	24 (26.7)	27 (42.2)	51 (33.1)		
<u>Looked After Child at any point while attending CAMHS</u>					
Yes	24 (26.7)	8 (12.5)	32 (20.8)	4.56	0.03
No	66 (73.3)	56 (87.5)	122 (79.2)		
<u>Evidence of special educational needs while attending CAMHS</u>					
Yes	19 (21.1)	10 (15.6)	29 (18.8)	0.736	0.39
None/NR	71 (78.9)	54 (84.4)	125 (81.2)		
<u>Evidence of Child Protection involvement while attending CAMHS</u>					
Yes	12 (13.3)	1 (1.6)	13 (8.4)	6.705	0.01
None/NR	78 (86.7)	63 (98.4)	141 (91.6)		
<u>Evidence of Youth Offending Team involvement while attending CAMHS</u>					
Yes	7 (7.8)	7 (10.9)	14 (9.1)	0.452	0.50
None/NR	83 (92.2)	57 (89.1)	140 (90.9)		
<u>Refugee or asylum seeker while attending CAMHS</u>					
Yes	10 (11.1)	9 (14.1)	19 (12.3)	0.002	0.96
No	58 (64.4)	51 (79.7)	109 (70.8)		
NR	22 (24.4)	4 (6.3)	26 (16.9)		
<u>Any known broader social risks? (yes to any of above)</u>					
Yes	45 (50.0)	23 (35.9)	68 (44.2)	3.000	0.08
No	45 (50.0)	41 (64.1)	86 (55.8)		

Clinical and service use variables

Actual and potential referrals differ significantly (at the 10% significance level) in terms of parental attendance, admission to hospital, detention under MHA, being on medication at time of transition, diagnostic categories of serious and enduring mental illness, eating disorders, substance misuse, emerging personality disorder, and significant comorbidity (Table 8). Actual referrals were significantly more likely (at the 5% significance level) to have attended CAMHS with their parents, been admitted to mental health hospital, to have been detained under the Mental Health Act and to have a serious and enduring mental disorder, substance misuse, an emerging personality disorder or more than one category of presenting problem (comorbidity); they were less likely to have an eating disorder.

Table 8. Clinical and service use variables comparing actual and potential referrals

	Actual referrals n (%)	Potential referrals n (%)	Total n (%)	Chi-Square	p value
<u>Parental attendance at CAMHS</u>					
Yes	34 (37.8)	20 (31.3)	54 (35.1)	11.643	0.003
No	33 (36.7)	39 (60.9)	72 (46.8)		
NR	23 (25.6)	5 (7.8)	28 (18.2)		
<u>Type of referral to CAMHS</u>					
Routine	46 (51.1)	48 (75.0)	94 (61.0)	1.425	0.23
Urgent	19 (21.1)	12 (18.8)	31 (20.1)		
not recorded	25 (27.8)	4 (6.3)	29 (18.8)		
<u>Discipline of key-worker at time of transition</u>					
Psychiatrists	35 (38.9)	23 (35.9)	58 (37.7)	4.797	0.31
Nurse (CPN/ Forensic/CNS/MHN)	16 (17.8)	8 (12.5)	24 (15.6)		
Psychologist	15 (16.7)	9 (14.1)	24 (15.6)		
Social worker, therapist, OT, psychotherapist, other	22 (24.4)	18 (28.1)	40 (26.0)		
NR	2 (2.2)	6 (9.4)	8 (5.2)		
<u>Evidence of admission to hospital for mental health problems while attending CAMHS</u>					
Yes	31 (34.4)	3 (4.7)	34 (22.1)	19.251	<.0001
None/NR	59 (65.6)	61 (95.3)	120 (77.9)		
<u>Detained under a section of the MHA at any point while attending CAMHS</u>					
Yes	15 (16.7)	1 (1.6)	16 (10.4)	9.165	0.002
No/NR	75 (83.3)	63 (98.4)	138 (89.6)		
<u>Presenting problem by category at time of transition (may be more than one)</u>					

Serious and enduring mental disorder	Yes	32 (35.6)	2 (3.1)	34 (22.1)	22.866	<.0001
	No	58 (64.4)	62 (96.9)	120 (77.9)		
Emotional/neurotic disorder	Yes	43 (47.8)	35 (54.7)	78 (50.6)	0.714	0.40
	No	47 (52.2)	29 (45.3)	76 (49.4)		
Eating disorder	Yes	1 (1.1)	5 (7.8)	6 (3.9)	4.486	0.03
	No	89 (98.9)	59 (92.2)	148 (96.1)		
Conduct disorder	Yes	3 (3.3)	3 (4.7)	6 (3.9)	0.183	0.67
	No	87 (96.7)	61 (95.3)	148 (96.1)		
Neurodevelopmental disorder	Yes	19 (21.1)	19 (29.7)	38 (24.7)	1.48	0.22
	No	71 (78.9)	45 (70.3)	116 (75.3)		
Substance misuse	Yes	12 (13.3)	2 (3.1)	14 (9.1)	4.716	0.03
	No	78 (86.7)	62 (96.9)	140 (90.9)		
Emerging personality disorder	Yes	4 (4.4)	0 (0.0)	4 (2.6)	2.92	0.09
	No	86 (95.6)	64 (100)	150 (97.4)		
<u>Comorbidity at time of transition</u>						
0 or 1 category		67 (74.4)	58 (90.6)	125 (81.2)	6.41	0.01
2 or more categories		23 (25.6)	6 (9.4)	29 (18.8)		
<u>Evidence of self-harm at time of transition</u>						
Yes		5 (5.6)	7 (10.9)	12 (7.8)	1.508	0.22
No/NR		85 (94.4)	57 (89.1)	142 (92.2)		
<u>On medication at time of transition</u>						
Yes		69 (76.7)	29 (45.3)	98 (63.6)	15.89	<.0001
No/NR		21 (23.3)	35 (54.7)	56 (36.4)		

Summary of univariate analysis for the purposes of the logistic regression

The following variables were significantly associated with achieving transition with p-values less than 0.1: age, first language, accommodation, family history of mental health difficulties, Looked After Child, child protection involvement, parental attendance, admission, admitted under the Mental Health Act (MHA), serious and enduring mental illness, eating disorder, substance misuse, emerging personality disorder, on medication, and comorbidity.

Logistic regression

Composite and retained variables

Being a Looked After Child and on the child protection register were highly related, $\chi^2=14.3$, $p<0.0001$. Therefore, a variable 'known broader social risks' was created which was equal to 1 if any of the following were present: Looked After Child, child protection involvement, Youth Offending Team

involvement, special educational needs, or refugee/asylum seeker. This new variable was marginally associated with achieving transition at the 10% level, $X^2=3.0$, $p=0.083$. We examined this further by creating a scored variable for social risk (0 – 5) with 1 assigned to each of the previous five variables; thus the higher the score, the greater the number of social risks the service user had. A Mann Whitney U test indicated there was a weak relationship between the strength of the score and whether a case was an actual or potential referral ($U=2449$, $p=0.078$). This variable was therefore also entered into the logistic regression.

Being admitted to an inpatient mental health unit and being admitted under the MHA were also highly associated, $X^2=63.0$, $p<0.0001$. Therefore, a composite variable was created with the three following categories: not admitted, admitted, admitted under the MHA. This variable was associated with achieving transition, $X^2=19.3$, $p<0.0001$.

Accommodation type and parental attendance were highly associated, $X^2=21.2$, $p<0.0001$. Parental attendance was, however, retained in the analysis as a separate variable. The reasoning was that, if found to be predictive of achieving transition, it is a potentially modifiable variable; i.e. children who do not have parents available to attend appointments could be provided with advocates.

Being on medication at the time of transition and having a serious and enduring mental disorder were highly associated, $X^2=14.3$, $p<0.0001$. The research team felt that both these variables were independently important, so regression models were fitted with each variable to examine their respective association with outcome. Although there is weak evidence of an association between emerging personality disorder and achieving transition, this variable has not been included in the logistic regression as only four service users were allocated to this category and they all made the transition.

Logistic regression results including serious and enduring mental illness or medication variable

Tables 9 and 10 show the results of the logistic regression, including serious and enduring mental illness and medication variables, respectively.

Table 9. Results of logistic regression (including serious and enduring mental illness variable): factors predicting actual transition

Independent variable		OR	95% CI	p-value
Known broader social risk (score)		1.38	0.90, 2.10	0.14
English as first language	Yes	1	-	-
	No	0.76	0.25, 2.32	0.62
Parents attend CAMHS	Yes	1	-	-
	No	0.56	0.23, 1.33	0.19
	NR	1.57	0.42, 5.86	0.5
Admitted as psychiatric inpatient	No	1	-	-
	Admitted	5.05	0.95, 26.79	0.05
	Admitted under section	4.99	0.52, 48.34	0.16
Eating disorder	No	1	-	-
	Yes	0.24	0.02, 2.37	0.22
Substance misuse	No	1	-	-
	Yes	1.66	0.25, 10.99	0.59
Comorbidity	No	1	-	-
	Yes	2.82	0.85, 9.41	0.09
Serious and enduring illness	No	1	-	-
	Yes	7.85	1.63, 37.78	0.01

Table 10. Results of logistic regression including medication variable

Independent variables		OR	95% CI	p-value
Known broader social risk (score)	Yes	1.44	0.93, 2.21	0.09
English as first language	Yes	1	-	-
	No	0.60	0.19, 1.86	0.4
Parents attend CAMHS	Yes	1	-	-
	No	0.47	0.20, 1.08	0.08
	NR	1.28	0.36, 4.48	0.7
Admitted as psychiatric inpatient	No	1	-	-
	Admitted	4.97	1.00, 24.76	0.05
	Admitted under section	8.39	0.99, 70.87	0.05
Eating disorder	No	1	-	-
	Yes	0.32	0.03, 3.27	0.34
Substance misuse	No	1	-	-
	Yes	1.61	0.25, 10.39	0.62
Comorbidity	No	1	-	-
	Yes	2.95	0.87, 10.02	0.08
On medication	No	1	-	-
	Yes	2.36	1.05, 5.33	0.04

Summary of logistic regression analysis

When serious and enduring mental illness is entered into the logistic regression, young people admitted to an inpatient unit were five times more likely than those not admitted to be an 'actual' referral (95% CI: 0.95, 26.79, $p=0.05$). There is a similar odds ratio when comparing those who were detained under the MHA to those not admitted but this is non-significant, probably due to small numbers. People with serious and enduring illness are significantly more likely to be 'actual' referrals than those with other diagnoses, OR=7.85 (95% CI: 1.63, 37.78, $p=0.01$).

When being on medication at the time of transition is entered into the logistic regression, young people admitted to inpatient units were again almost five times more likely than those not admitted to be an 'actual' referral (95% CI: 1.00, 24.76, $p=0.05$). Young people who had been admitted under the MHA were 8.39 times more likely than those not admitted to be an 'actual' referral (95% CI: 0.99, 70.87, $p=0.05$). Young people on medication at the time of transition are significantly more likely to be 'actual' referrals than those not, OR=2.36 (95% CI: 1.05, 5.33, $p=0.04$).

Together these analyses suggest that severe and enduring mental illness, severe enough to require admission to hospital, whether or not under the

Mental Health Act, or to require medication, is the factor most likely to predict a transition to AMHS.

3.5.5 Optimal transitions: cases

Four criteria were used to define an optimal transition. These were:

- continuity of care (either engaged with AMHS three months post-transition or appropriately discharged); AND
- a period of parallel care (a period of joint working where the service user is involved with both CAMHS and AMHS); AND
- at least one transition planning meeting (meeting discussing the transition from CAMHS to AMHS, involving the service user and/or carer and key professionals, prior to the handover of care from CAMHS to AMHS); AND
- optimal information transfer (any or all of the following transferred from CAMHS to AMHS: referral letter, summary of CAMHS contact, any or all CAMHS notes and a contemporary risk assessment).

Based on these criteria only four of the 90 actual referrals experienced an optimal transition. They were 2 males and 2 females and were all from ethnic minority backgrounds. Three had a diagnosis of a serious and enduring mental disorder at the time of transition and had been admitted to hospital at some point while attending CAMHS (two under MHA). All four were on medication at the time of transition. All four cases were in two of the London Trusts: L2 (n=2) and L3 (n=2). Three cases (service users B, D and L) were referred from adolescent CAMHS teams, and all were referred onto CMHTs, although one case, service user G, is now with an Early Intervention (EI) team which was part of the CMHT to which he was referred. Service users B, D and L were all age 18 at the time of transition and service user G was age 19. These cases are described in Table 11 below.

Table 11. Cases with optimal transitions

ID	Diagnosis at time of transition	Admitted to hospital	On Meds?	Gender	Ethnicity	Trust
Service user L	Bipolar affective disorder	Yes (not on section MHA)	Yes	Female	Black	L2
Service user D*	Bipolar affective disorder	Yes (on section 2)	Yes	Female	Black	L3
Service user G*	Psychotic disorder	Yes (on section 3)	Yes	Male	Black	L3
Service user B*	Depression	No	Yes	Male	Asian	L2

* Interviewed in Stage 4

Suboptimal transitions: cases

Suboptimal transitions were defined as those cases that failed to meet one or more of the above criteria. The breakdown of the components of optimal transition, for the 90 actual referrals, are as follows (see Figure 6):

22/90 (24.4%) had a period of parallel care/joint working between CAMHS and AMHS, of whom 8 (8.9% of actual referrals) had a transition planning meeting (TPM), 6 (6.7%) had good information transfer and 18 (20.0%) had continuity of care;

36/90 (40.0%) had at least one transition planning meeting, of whom 8 (8.9% of actual referrals) had a period of parallel care, 16 (17.8%) had good information transfer and 28 (31.1%) had continuity of care;

24/90 (26.7%) had good information transfer of whom 6 (6.7% of actual referrals) had a period of parallel care, 16 (17.8%) had at least one transition planning meeting and 20 (22.2%) had continuity of care; and

63/90 (70.0%) had continuity of care, of whom 18 (20.0% of actual referrals) had a period of parallel care, 28 (31.1%) had at least one transition planning meeting and 20 (22.2%) had good information transfer (see Figure 7).

Overall, actual referrals most often had continuity of care followed in decreasing order to also have had at least one transition planning meeting, good information transfer and a period of parallel care/joint working between CAMHS and AMHS. Thirteen out of the 90 actual referrals had none of the TRACK components of optimal transition (see Figure 8).

Figure 6. Numbers of cases meeting the constituent criteria for optimal transition

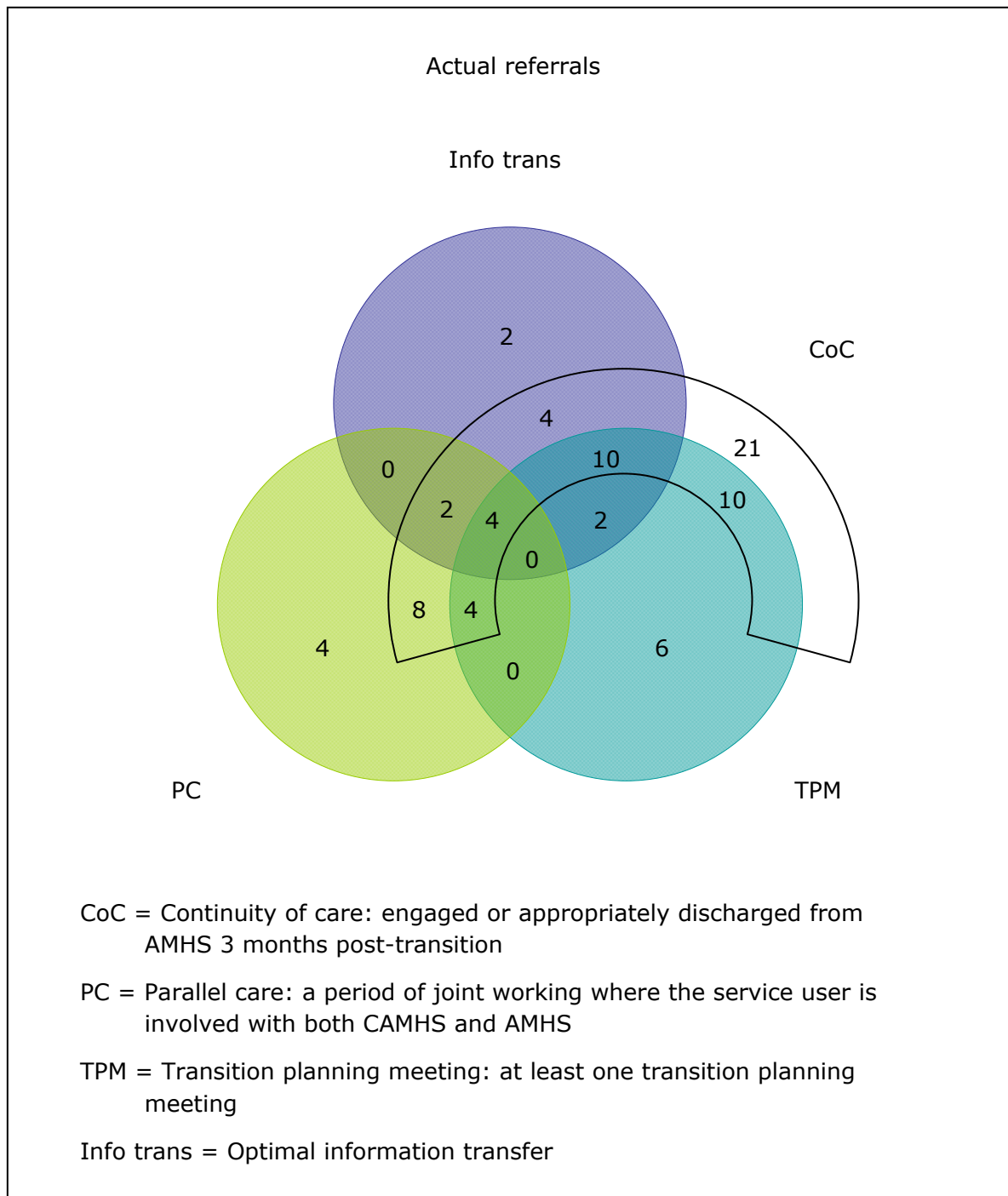


Figure 7. Numbers of cases with continuity of care meeting the other constituent criteria for optimal transition

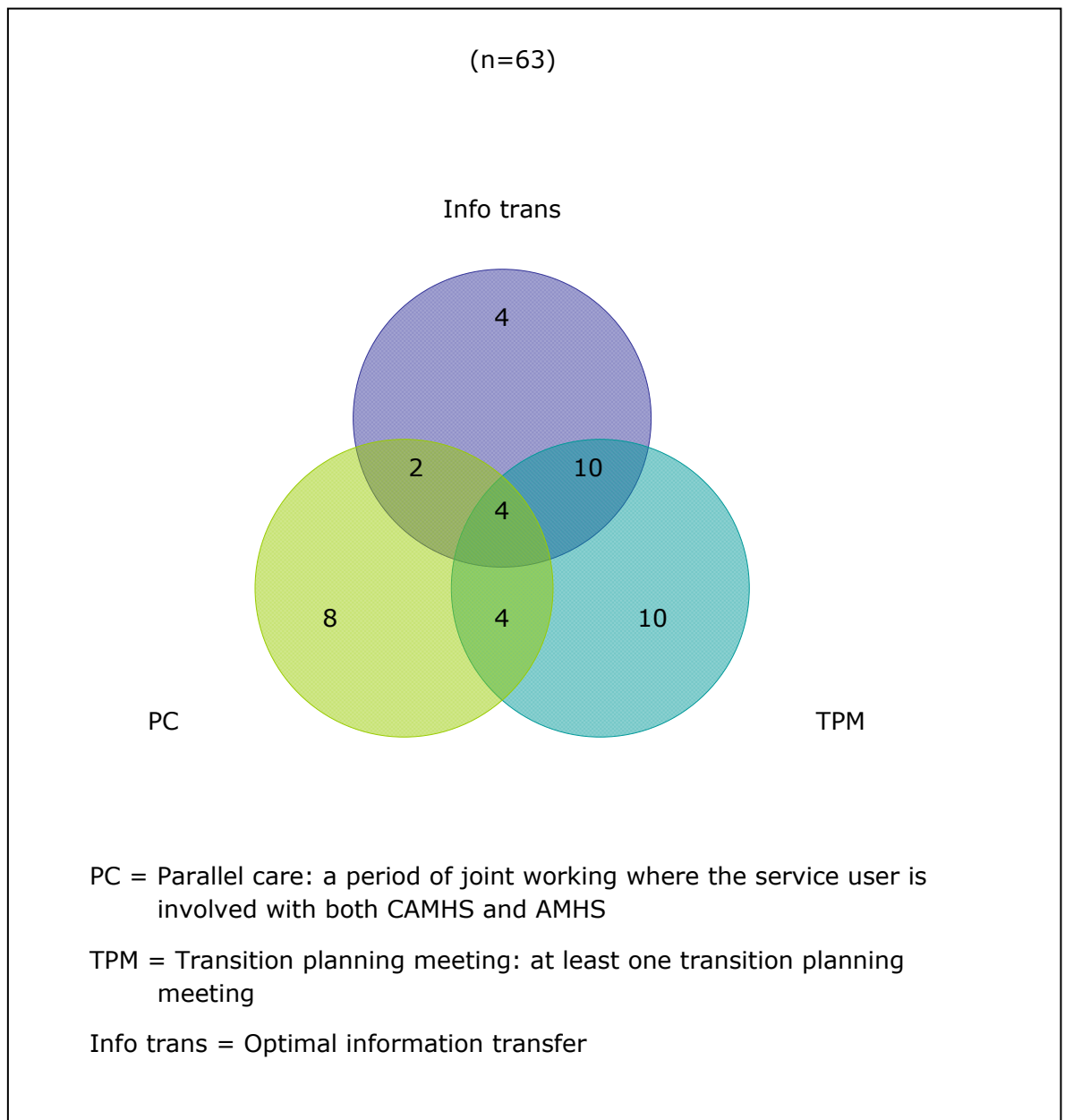
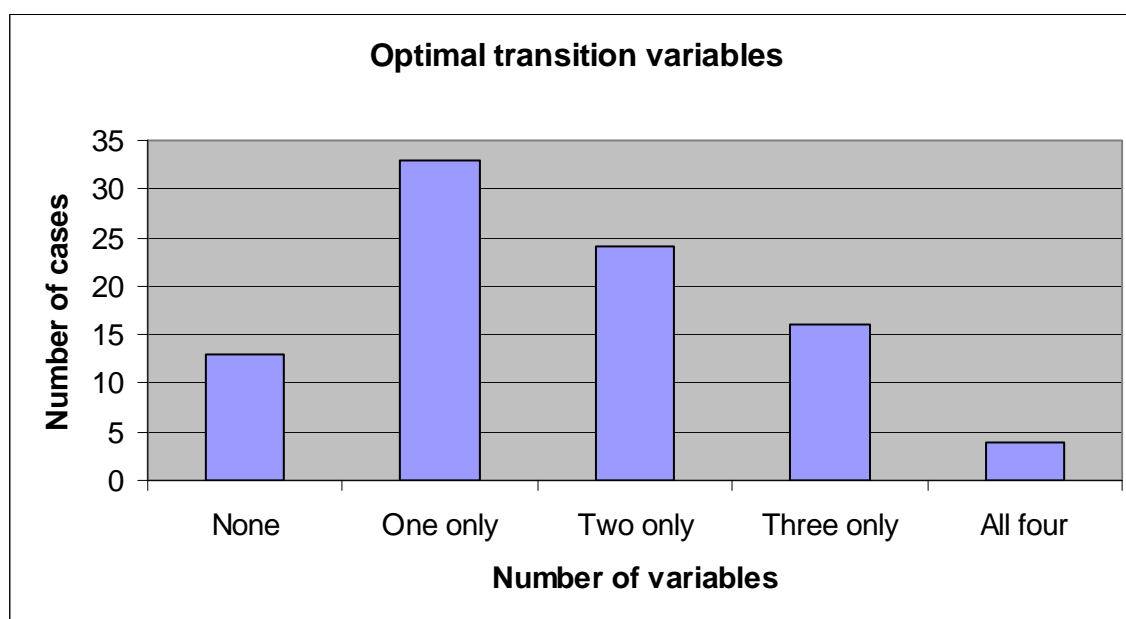


Figure 8. Cases with any or all of the optimal transition variables

3.5.6 Optimal transitions: predictors of experiencing continuity of care

The criteria agreed to define continuity of care were 'still engaged with AMHS or appropriately discharged 3-months post-transition'. Univariate analysis of actual referrals at the 10% level indicated that continuity of care was more likely for those cases where young people had married/cohabiting parents or a serious and enduring mental illness. Continuity of care was less likely for those with emotional/neurotic disorder or an emerging personality disorder. Only the latter two retain significance at the 5% level. The following tables provide details of the comparison of cases that did and those that did not experience such continuity of care in relation to demographic, social risk and service use / disorder variables, among all those cases that were referred to and accepted by AMHS (i.e. actual referrals).

Table 12. Association of demographic variables with continuity of care

	Actual referrals with continuity of care (COC) * n (%)	Actual referrals without COC n (%)	Chi- Square	p value
Male	35 (55.6)	14 (51.9)	0.105	0.746
Mean_age at first referral to any CAMHS	13.56 (n=61)	12.85 (n=27)	t=.780	0.438
Std Dev.	3.823	4.12		
<u>Ethnicity</u>				
Asian	7 (11.1)	1 (3.7)	2.352	0.671
Black	16 (25.4)	7 (25.9)		
Mixed/Other	10 (15.9)	3 (11.1)		
White	16 (25.4)	10 (37.0)		
NR	14 (22.2)	6 (22.2)		
<u>Language</u>				
English as first language / NR	57 (90.5)	25 (92.6)	0.11	0.746
First language other	6 (9.5)	2 (7.4)		
<u>Accommodation</u>				
Parent(s)' home	42 (66.7)	16 (59.3)	1.783	0.410
On own	10 (15.9)	3 (11.1)		
Other	11 (17.5)	8 (29.6)		
<u>Highest education reached to date</u>				
GCSEs and below	31 (49.2)	11 (40.7)	0.544	0.762
above GCSEs	24 (38.1)	12 (44.4)		
NR	8 (12.7)	4 (14.8)		
<u>Evidence that young person is in education and/or employment</u>				
Yes	44 (69.8)	14 (51.9)	2.669	0.102
No/NR	19 (30.2)	13 (48.1)		
<u>Parental status</u>				
Married/cohabiting - 2 parents	22 (34.9)	3 (11.1)	7.175	0.067
Separated/divorced	28 (44.4)	16 (59.3)		
1 or 2 parents deceased	10 (15.9)	4 (14.8)		
Other/NR	3 (4.8)	4 (14.8)		
<u>Family history of mental health difficulties</u>				
Yes	36 (57.1)	15 (55.6)	0.518	0.472

No	12 (19.0)	3 (11.1)		
NR	15 (23.8)	9 (33.3)		

* Continuity of care: engaged with AMHS or appropriately discharged three months post-transition

Table 13. Association of broader social risks with continuity of care

	Actual referrals with COC n (%)	Actual referrals without COC n (%)	Chi-Square	p value
<u>Looked After Child at any point while attending CAMHS</u>				
Yes	15 (23.8)	9 (33.3)	0.877	0.349
No	48 (76.2)	18 (66.7)		
<u>Evidence of special educational needs while attending CAMHS</u>				
Yes	12 (19.0)	7 (25.9)	0.537	0.464
None/NR	51 (81.0)	20 (74.1)		
<u>Evidence of Child Protection involvement while attending CAMHS</u>				
Yes	8 (12.7)	4 (14.8)	0.073	0.787
None/NR	55 (87.3)	23 (85.2)		
<u>Evidence of YOT involvement while attending CAMHS</u>				
Yes	4 (6.3)	3 (11.1)	0.597	0.440
None/NR	59 (93.7)	24 (88.9)		
<u>Was the YP a refugee or asylum seeker at any time while attending CAMHS?</u>				
Yes	8 (12.7)	2 (7.4)	0.817	0.366
No	38 (60.3)	20 (74.1)		
NR	17 (27.0)	5 (18.5)		

Table 14. Service use / disorder variables for continuity of care

	Actual referrals with COC	Actual referrals without COC	Chi-Square	<i>p</i> value
<u>Parental attendance at CAMHS</u>				
Yes	26 (41.3)	8 (29.6)	3.851	0.146
No	19 (30.2)	14 (51.9)		
NR	18 (28.6)	5 (18.5)		
<u>Type of referral to CAMHS</u>				

Routine	29 (46.0)	17 (63.0)	0.680	0.410	
Urgent	14 (22.2)	5 (18.5)			
not recorded	20 (31.7)	5 (18.5)			
<u>Was the referring CAMHS an adolescent team?</u>					
Yes	23 (36.5)	10 (37.0)	0.002	0.962	
No	40 (63.5)	17 (63.0)			
<u>Was the accepting AMHS an EI team?</u>					
Yes	9 (14.3)	3 (11.1)	0.165	0.685	
No	54 (85.7)	24 (88.9)			
<u>Was the accepting AMHS a CMHT?</u>					
Yes	35 (55.6)	16 (59.3)	0.494	0.781	
No	27 (42.9)	11 (40.7)			
NR	1 (1.6)	0 (0.0)			
<u>Discipline of key-worker at time of transition</u>					
Psychiatrists	25 (39.7)	10 (37.0)	1.585	0.811	
Nurse (CPN/Forensic/CNS/MHN)	12 (19.0)	4 (14.8)			
Psychologist	10 (15.9)	5 (18.5)			
Social worker, therapist, OT, psychotherapist, other	14 (22.2)	8 (29.6)			
NR	2 (3.2)	0 (0.0)			
<u>Evidence of admission to hospital for mental health problems while attending CAMHS</u>					
Yes	22 (34.9)	9 (33.3)	0.021	0.885	
None/NR	41 (65.1)	18 (66.7)			
<u>Detained under a section of the MHA at any point while attending CAMHS</u>					
Yes	12 (19.0)	3 (11.1)	0.857	0.355	
No/NR	51 (81.0)	24 (88.9)			
<u>Presenting problem by category at time of transition (may be more than one)</u>					
Serious and enduring mental d/o	Yes	26 (41.3)	6 (22.2)	2.993	0.084
Emotional/neurotic disorder	Yes	26 (41.3)	17 (63.0)	3.565	0.048
Eating disorder	Yes	1 (1.6)	0 (0.0)	0.433	0.510
Conduct disorder	Yes	3 (4.8)	0 (0.0)	1.330	0.249
Neurodevelopmental disorder	Yes	14 (22.2)	5 (18.5)	0.156	0.693
Substance misuse	Yes	8 (12.7)	4 (14.8)	0.073	0.787
Emerging personality disorder	Yes	1 (1.6)	3 (11.1)	4.037	0.045
<u>Comorbidity at time of transition</u>					
0 or 1 category		48 (76.2)	19 (70.4)	0.337	0.562

2 or more categories	15 (23.8)	8 (29.6)		
<u>Evidence of self-harm at time of transition</u>				
Yes	3 (4.8)	2 (7.4)	0.252	0.616
<u>On medication at time of transition</u>				
Yes	51 (81.0)	18 (66.7)	2.156	0.142
No/NR	12 (19.0)	9 (33.3)		

Summary of univariate analysis for the purposes of the logistic regression

At a univariate level, continuity of care was more likely for those cases where young people had married/cohabiting parents or a serious and enduring mental illness. Continuity of care was less likely for those with emotional/neurotic disorder or an emerging personality disorder.

Logistic regression

Composite and retained variables

Serious and enduring mental illness and emotional/neurotic disorder were highly negatively associated, $X^2=34.3$, $p<0.0001$. This was because the two variables were virtually mutually exclusive with only 2 people having both disorders. The logistic regression was fitted twice, once with serious and enduring mental illness, parental status and emerging personality disorder and then with emotional/neurotic disorder, parental status and emerging personality disorder.

Logistic regression results

Tables 15 and 16 illustrate the results of logistic regressions predicting suboptimal continuity of care including emotional/neurotic disorder and serious and enduring mental illness variables.

Table 15. Results of logistic regression (including emotional/neurotic disorder variable): factors predicting suboptimal continuity of care

Independent variables		OR	95% CI	p-value
Parental status	Married/cohabiting	1	-	-
	Separated/divorced	0.23	0.06, 0.97	0.04
	1 or 2 parents deceased	0.32	0.06, 1.75	0.19
	Other/NR	0.13	0.02, 0.93	0.04
Emerging personality disorder	No	1	-	-
	Yes	0.12	0.01, 1.39	0.09
Emotional/neurotic disorder	No	1	-	-
	Yes	0.34	0.12, 0.96	0.04

Table 16. Results of logistic regression (including serious and enduring mental illness variable): factors predicting suboptimal continuity of care.

Independent variables		OR	95% CI	p-value
Parental status	Married/cohabiting	1	-	-
	Separated/divorced	0.27	0.07, 1.08	0.06
	1 or 2 parents deceased	0.32	0.06, 1.72	0.18
	Other/NR	0.11	0.02, 0.79	0.03
Emerging personality disorder	No	1	-	-
	Yes	0.21	0.02, 2.27	0.2
Serious and enduring illness	No	1	-	-
	Yes	2.08	0.70, 6.25	0.18

Individuals with emotional/neurotic disorder appear to be a third less likely to experience optimal continuity of care (95% CI: 0.12, 0.96, $p=0.04$), i.e. they are less likely to experience continuity of care than those with other conditions. Having parents who are married or cohabiting predicts optimal continuity of care in cases with both neurotic disorders and serious and enduring mental illnesses. Other categories identified by univariate analysis as significantly associated with continuity of care, were not supported as predictors of optimal continuity when assessed by the logistic regression. This included having a serious and enduring mental illness.

Transition process measures for cases with and without continuity of care

Table 17 shows comparison of cases that did and those that did not experience continuity of care. Of the actual referrals, 24% ($n=22$) had a period of parallel care and 31% ($n=28$) had a least one transition planning meeting. Twenty-seven percent ($n=24$) had optimal information transfer, but only 4% ($n=4$) had all of these measures.

Table 17. Association of transition process measures with continuity of care

	Actual referrals with COC n (%)	Actual referrals without COC n (%)	Chi-Square	p value
1) optimal parallel care	18 (29)	4 (15)	1.94	0.192
suboptimal parallel care	45 (71)	23 (85)		
2) optimal TPM*	28 (44)	8 (30)	1.73	0.189
suboptimal TPM	35 (56)	19 (70)		
3) optimal information transfer	20 (32)	4 (15)	2.77	0.096

suboptimal information transfer	43 (68)	23 (85)		
---------------------------------	---------	---------	--	--

*TPM = at least one transition planning meeting.

Overall, none of the other components of optimal transition (period of parallel care, at least one transition planning meeting, and good information transfer) significantly predicted continuity of care, although the best indicator was good information transfer, for which there was weak association with continuity of care ($p=0.09$).

3.6 Discussion

3.6.1 Identifying actual and potential referrals

Case ascertainment

Stage 2 aimed to identify all actual and potential referrals from CAMHS to AMHS in the preceding year and track their transition and outcomes. Case ascertainment was conducted using a dual strategy of searching CAMHS and AMHS central databases and asking individual clinicians to identify actual and potential referrals within their caseloads in the preceding year. There were significant problems in case ascertainment in both strategies. Databases either did not exist or could not provide accurate and suitable information needed for the study. Some clinicians felt too busy to provide relevant information, some could not be contacted because of staff turnover, and some could not accurately recall appropriate cases because of high caseloads. While the study managed to recruit enough cases as per the original protocol, our rates of actual and potential referrals are likely to be underestimates.

If such extensive and prolonged research does not succeed in getting accurate information about transition from CAMHS to AMHS, then it is highly unlikely that service commissioners and providers have any information on which to develop, evaluate and improve services or understand the needs, outcomes and experiences of young people undergoing transition. The lack of central databases in mental health services and the poor quality of information available appear major impediments for both service evaluation and service development. TRACK is a good example of research making an important contribution to 'assessing the completeness and quality of data used for clinical care and health services' (UKCRC Advisory Group for Connecting for Health, 2007, p6).

There are several new initiatives in Information Technology developments with the NHS including Connecting for Health (www.connectingforhealth.nhs.uk). In conjunction with the UK Clinical Research Collaboration (UKCRC), its Research Capability Programme states that its '... primary objective is to enable research to achieve its full potential as a "core" activity for health care, alongside other uses of NHS data that lead to improvements in the quality and safety of care'. This has been reiterated by the Department of Health document *Best Research for Best Health - A New National Health Research Strategy* (Department of

Health, 2006a). The Department of Health has also commissioned the National Datasets Service of The NHS Information Centre for Health and Social Care to develop a CAMHS dataset (www.ic.nhs.uk/services/datasets/dataset-list/camhs) to support the implementation for the National Service Framework for Children, Young People and Maternity Services. It takes into account the CAMHS Outcome Research Consortium (CORC, <http://www.corc.uk.net/>) dataset and proposes to take into account the National Institute for Clinical Excellence (NICE) guidelines and related work. The current consultation version includes subsets on care planning including transition to AMHS (Information Centre for Health and Social Care, 2008). TRACK findings clearly illustrate the need for such improvements in central databases; whether these policy aspirations will be realised is a question for the future.

Data extraction from case notes

We encountered major difficulties in finding and searching case notes. CAMHS case notes were in different ways or different places depending on the team, and searching for closed cases required considerable time and effort by researchers, clinicians and administrative staff. For instance, files were sometimes located in damp, dark rooms in dusty boxes, in no particular order, or researchers found themselves climbing over filing cabinets in order to retrieve a file, only to find much of the information needed missing. On occasion, files appeared to be missing without any trace. For located files, data extraction was difficult since the way notes were organised varied between and sometimes even within each team, email and telephone contact was rarely recorded properly, and handwritten clinical notes were often difficult and sometimes impossible to read. This raised concerns about the accuracy of the data, especially about the nature and frequency of clinical contacts, types of interventions delivered, transition planning and discussions, discussions with users and carers, and the information transferred to AMHS. Accessing AMHS case notes to follow up actual referrals also posed challenges. Some teams demanded additional paperwork prior to allowing access despite R&D ethical approval, there was a lack of consistency between teams as to who should be contacted (e.g. consultant, team manager, care co-ordinator) and by what method (e.g. phone, letter, fax, or email), and service user being seen by an AMHS team different to the one specified in the CAMHS case notes. Overall, the accessibility, organisation and quality of case notes made this retrospective case note survey an extremely labour intensive task. Like the central databases, clinical information within medical notes appeared not conducive to research and analysis. In an era that demands both evidence-based practice and increased scrutiny of the quality of care provision, the TRACK experience suggests that major attitudinal and practical changes are needed in how clinical information is collected and recorded.

Tier 4 limitations

We could not include Tier 4 cases from any study site. No local inpatient adolescent units in our West Midlands site meant that all those requiring inpatient care were admitted elsewhere. Tracking cases from tier 4 national

and specialist services in our Greater London sites, where service users came from trusts across the region or the country would have entailed seeking data from trusts not participating in TRACK.

Tier 4 inpatient services may well have specific transition issues not picked up by TRACK. The National Inpatient Child and Adolescent Psychiatry Study (NICAPS) (O'Herlihy, Worrall, Banerjee, Jaffa, Hill, Mears, Brook, Scott, White, Nikolaoou and et al, 2001) undertook a census of inpatient units, in which 71 (89%) of the 80 identified CAMHS inpatient units returned information on 663 young people. The majority were aged 15-18 years and 21 inpatients were over the age of 18. The NICAPS study highlighted the scarcity of emergency provision, a main concern of community (tier 2/3) CAMHS. Shortage of emergency provision contributes to inappropriate admission to adult mental health units (Gowers, 2003). Over the next few years research will be needed to evaluate the development of age-appropriate service as required by the 2007 amendments to the Mental Health Act 1983.

Rates of actual and potential transitions

Our rates of actual and potential referrals per 100,000 population in the London sites were 2.68 and 1.49 respectively, the corresponding figures for the West Midlands sites were 2.23 and 2.97 respectively. For reasons discussed above, these figures are likely to be underestimates and should be used as the lower limit of the true range. Our methodology also cannot identify trends and variations in these rates and the potential reasons for such variations, such as local service organisation, case mix and variations due to the characteristics of the local population.

3.6.2 Sample description

Demographics

The total sample (both actual and potential referrals) consisted of 78 (51%) males and 76 females, with a mean age of 18.12 years (SD 0.824) at the time of data collection. The majority ethnic group was White (31%), followed by Black (23%), although no ethnicity was recorded for a large portion of the sample (27%). The total proportion of Black and Minority Ethnic (BME) cases was 66/154 (43%). The majority (76%) spoke English as their first language. Most of the young people in the sample lived with their parents (71%) and the majority (60%) were either in employment or education.

The relatively proportion of BME cases is not unexpected, given the geographical areas studied. CAMHS has traditionally thought to be poorly accessible to and used by BME families (Malek and Joughin, 2004). Young people from BME backgrounds have specific issues that impede access and use of services including concerns around discrimination, racism, confidentiality, family and community pressures, uncertainty about services and stigma of mental illness. Within CAMHS provision there is a relative lack

of services targeted to BME communities in particular and about cultural competence in general (Kurtz and Street, 2006).

Presenting problems

We found significant variation in how CAMHS clinicians recorded presenting problems and diagnoses at the time of transition. This possibly reflects ambivalence among some CAMHS clinicians about 'medicalising' children's problems. This was also noted in the national CAMHS Review (National CAMHS Review, 2008, s6.25, p66) which states: 'A specific example of this is the requirement within some health trusts to record diagnoses of all children and young people seen within CAMHS. This has met with concern from some professional disciplines, who see such an approach as "medicalising" children's problems. While accurate diagnosis remains important for some specific types of disorder, the eventual implementation of a CAMHS dataset (see paragraph 7.29), which incorporates a problem-focused approach, should help to address this issue'. In TRACK we were keen to use categories consistent with the way most child and adolescent clinicians reason as well as categories that might have relevance for transition and specialist adult services (e.g. Eating Disorder Services). The categories used were discussed and refined in an iterative way by the TRACK steering group. In relation to 'emerging personality disorder', there are no contemporaneous, widely accepted assessment schedules or adolescent-specific diagnostic criteria for adolescent Personality Disorder (PD). Indeed the American Psychiatric Association (2000) and World Health Organisation (1992) caution against using their PD criteria in under-18s (Chanen, Jackson, McCutcheon, Jovev, Dudgeon, Yuen, Germano, Nistico, McDougall and Weinstein, 2008). Some child and adolescent psychiatrists are reticent to diagnose PD in young people since personality development is as yet incomplete, the label of PD is stigmatising and a view that PD presentations can be explained using other Axis I constructs (Ma, 2005; Chanen *et al*, 2008). In addition, there remains debate about the classification of PDs, especially when adult PDs are discussed in terms of categories, dimensions and clusters (Tyrer, Coombs, Ibrahim, Mathiakath, Bajaj, Ranger, Rao and Din, 2007), while adolescent PDs have been conceptualised using types (i.e. adult PD categories), prototypes (i.e. of adult PD categories) and traits (Westen, Dutra and Shedler, 2005). On the other hand, there is growing evidence, especially from the USA, that personality pathology is a significant form of psychopathology in young people (Westen *et al*, 2005). Research is starting to address the need for evidence-based interventions for young people with such conditions, especially because of the high morbidity, impaired functioning and high levels of concern about such young people (Chanen *et al*, 2008). Recent papers suggest long-term poor psychosocial adjustment predicted by presence of adolescent PD (Crawford, Cohen, First, Skodol, Johnson and Kasen, 2008). We found that emerging personality disorder and personality-related mental health issues were reasons for seeking referral to AMHS.

Learning Disability services have established procedures and policy-related toolkits and guidance for managing transition (Department for Education and Skills and Department of Health, 2006; Department for Children

Schools and Families and Department of Health, 2008). Young people with generalised learning disabilities not being managed by CAMHS were therefore not included in TRACK. Young people with specific learning difficulties, such as dyslexia without concomitant psychopathology also do not undergo transition to AMHS, hence were not included in TRACK. However, young people with generalised or specific learning difficulties who were attending CAMHS were included in the TRACK category 'neurodevelopmental disorders' along with those with pervasive developmental disorders and neurodevelopmental diagnoses such as Attention Deficit Hyperactivity Disorder.

About half the population that underwent transition fell into the diagnostic categories of emotional/neurotic disorders (51%), neurodevelopmental disorders (25%) and serious and enduring mental disorders (22%). Almost a fifth had more than one presenting problem at transition, most commonly comorbid emotional/neurotic disorders with neurodevelopmental disorders, and serious and enduring mental illness with substance misuse.

3.6.3 Transition pathways

Transfer of care

In TRACK Stage 1, the responding teams' estimated their average annual numbers suitable for transition as between 0 and 70 (mean 12.3, SD 14.5, $n=37$). Estimates of average annual number that actually made the transition ranged from 0 and 50 (mean 8.3, SD 9.5, $n=33$). Average numbers of service users who continued to be seen by CAMHS beyond the transitional boundary varied from 0 to 64 (mean 7.6, SD 11.8, $n=31$). The actual referral rates found in Stage 2 show that CAMHS professionals greatly underestimate the proportion of referrals that AMHS accept and overestimate the numbers CAMHS continue to see despite young people crossing the transition boundary.

As revealed by Stage 2 findings, four fifths of all cases who reached the transition boundary were thought by CAMHS clinicians to be suitable for transition. Of these, families refused referral in a tenth of cases and in another tenth, referrals were not made because CAMHS thought AMHS would either not accept referral or did have appropriate services. Almost four fifths of cases thought suitable for transition were referred to AMHS, and only 7% were not accepted by AMHS.

AMHS appear therefore to accept most referrals made by CAMHS, even though there is a widespread perception that they do not (Select Committee on Health, 2000; Singh *et al*, 2005; Lamb *et al*, 2008). Indeed, in TRACK fewer referrals were refused by AMHS than were not referred by CAMHS in the first place. TRACK is unable to confirm whether those cases not referred would, in reality, have been accepted by AMHS. In addition, clinicians who have adjusted to AMHS thresholds or assumed there is no adult service available will not be raising any unmet need. The concern should therefore not be about AMHS not accepting referrals from CAMHS, but about those who are never referred by CAMHS because of a perception that AMHS will

not accept these referrals or that appropriate services do not exist within AMHS. If CAMHS clinicians think that these young people have ongoing needs that should be met by AMHS, it is difficult to see why greater effort is not made, either by individuals from CAMHS contacting their counterparts in AMHS, or by discussion at a management level between CAMHS and AMHS managers about the unmet needs of these young people.

In summary TRACK reveals two very important findings: the perception that AMHS do not accept referrals is not factual, and that this misperception stops CAMHS clinicians from making appropriate referrals. One main message from this is that CAMHS clinicians should make referrals to AMHS, regardless of their perceptions about the unlikelihood of these referrals being accepted. If CAMHS perceive a service gap in AMHS, this should be raised at the management level, rather than leave young people with unmet need to fall through the CAMHS-AMHS gap.

There was regional variation in whether CAMHS provided services for young people up to the age of 18 years. Services in London did but the West Midlands Region sites did not. Thus, policy targets on extending CAMHS provision to the eighteenth birthday in Standard 9 of the Children's NSF (Department of Health and Department for Education and Skills, 2004) are only being met in some areas. The recent CAMHS review (National CAMHS Review, 2008) frames its recommendations on transitions in relation to young adults who are approaching 18 years of age and are seen at CAMHS, while acknowledging that many CAMHS struggle to effectively meet the needs of all young people until they reach eighteen.

Ongoing need: no transfer of care

The need for more AMHS or alternatives to AMHS?

In the 23.5% of cases where there was an ongoing clinical need but the service user was not referred on to AMHS or where AMHS did not accept the referral, the majority of cases had either the neurodevelopmental disorders or emotional/neurotic disorders categories. Almost half of potential referrals, whether not referred to AMHS, still with CAMHS or rejected by AMHS, were on medication. This raises major concerns about what happens to these young people and whether their medication is appropriately continued or monitored. Many adults with neurodevelopmental disorders like ADHD will continue to need treatment and have psychiatric comorbidity and complex problems (e.g. Young and Toone, 2000). Should AMHS extend its remit to care for this group or should there be an alternative provision? Lamb *et al* (2008) recommend that specific agreement should be reached between CAMHS and AMHS and protocols established for transition of young people with ADHD and autism spectrum disorders, among others. They also recommend that primary care, clinical psychology, Social Services and non-statutory organisations should work alongside mental health services to develop care pathways and transitional care for young adults with disorders other than psychotic or bipolar disorders. The Children's NSF (Department of Health and Department for Education and Skills, 2004) also recommends that arrangements for alternative provision should be made for those young

people who do not meet AMHS criteria (Department for Education and Skills and Department of Health, 2006). At this stage, there is no evidence for policy makers to decide which of the two strategies, extending AMHS provision or developing alternatives is effective from either a clinical or economic perspective. TRACK findings suggest that we should consider developing and evaluating several different models of transitional care for this group (see below and the Discussion section in this report).

No need for transfer to AMHS?

A group of young people were not referred to AMHS since they were thought to have 'no further clinical need'. Ninety percent came from the West Midlands sites and half were in the emotional/neurotic diagnostic category, with a quarter having eating disorders. A quarter were on medication at the time of crossing the transition boundary. It is possible that in these cases an episode of care was coming to an end and the 'flexibility' identified as important in transition protocols (see *section 2: Stage 1*) was being applied by CAMHS clinicians. The geographical variation, however, is harder to explain.

Transfer to AMHS refused

In the tenth of cases suitable for transition, families or users refused referral to AMHS. We are unable to explain the reasons behind this refusal and what CAMHS clinicians planned for meeting their needs. It might be that although CAMHS perceive a need, these families do not. It is also not clear whether this implies a gap in service provision or differences in how mental health problems are viewed and risks evaluated or communicated. Alternately, it may reflect the acceptability of AMHS services by young people and their carers (cf Royal College of General Practitioners, 2002). Many reports have noted the need to provide accessible services that are acceptable to and appropriate for young people (Pugh, McHugh and McKinstrie, 2006; YoungMinds, 2006a). Like similar recent research in the child health literature (McDonagh, 2006) we recommend future research on the 'why' question alongside the 'how many' question addressed by this stage of TRACK.

An important single outlier was the case where a parent refused transfer to AMHS and this decision was not shared (according to the notes) by the young person. Working with families raises complex ethical and legal issues, including duties of care, rights, consent and confidentiality (Paul, Berriman and Evans, 2008), especially at times of transition (Royal College of Physicians of Edinburgh Transition Steering Group, 2008). When parents refuse, CAMHS need to start seeking young people's views separately, as the main duty of care is to the young person. Successful transition also involves the young person learning about their condition, understanding the rationale for treatment and the need for transition, and developing self-efficacy and autonomy (Department of Health and Department for Education and Skills, 2004; Royal College of Physicians of Edinburgh Transition Steering Group, 2008). If parents have blocked appropriate

transition then perhaps these aspects of successful transition have not been considered with clinicians.

Non-attendance at AMHS

The high rates of non attendance (about a quarter) at first AMHS appointment is concerning. Stage 1 data showed that while service user and parent/carer involvement in transition planning was ubiquitous as a principle in transition policies, no policies specified ways of preparing them for transition. Such a preparation should also include an emphasis on engaging with AMHS. YoungMinds have made recommendations specifically relating to young people who either cannot access or who reject AMHS. They note that statutory mental health services tend to provide few treatment modalities and limited locations for services (cf CSIP Choice and Access Programme, 2006). These include designing services that are 'acceptable, accessible and appropriate for young adults' (YoungMinds, 2006a, p4), using a 'multi-agency, multi-problem and multi-disciplinary' (p17) approach. These issues will be returned to in TRACK Stage 4 (section 5).

The AMHS in our sites seem to have offered up to three appointments before closing a case and succeeded at seeing some young people at each round of appointments offered following missed appointments. Anecdotally, it is not uncommon for people working at CAMHS to have heard the sentiments 'AMHS only offer one appointment and close if it isn't attended'. TRACK findings suggest this is not an evidence-based statement.

It remains a significant concern that about a fifth of cases referred to and accepted by AMHS were discharged without being seen. Reasons identified from the case notes included non-response to attempts to arrange an appointment and failure to attend the first, and sometimes subsequent appointments offered, as well as, on very few occasions, no appointment being sent or non-response to AMHS attempts to arrange appointments. Again, further research is required to establish the outcomes of these young people who are never seen by AMHS. Stage 4 (section 5) will explore young people's reasons for engagement and disengagement with AMHS.

In terms of teams, there was no pattern suggesting that specific adult service types did not accept referrals from CAMHS, although we note that TRACK Stage 4 interviews revealed that additional transfers to other teams are not unusual (section 5). No unsuccessful referrals were made to Early Intervention in Psychosis Teams, suggesting that at least in early psychosis, there is clear consensus between CAMHS and AMHS about suitability of transition.

3.6.4 Predictors for achieving transition from CAMHS to AMHS: actual v potential referrals

Logistic regression analyses suggest that severe and enduring mental illness, severe enough to require admission to hospital, whether or not under the Mental Health Act, and requiring medication were most likely to predict making a transition to AMHS. In one way, this is a positive finding as

those at highest risk (Simmonds, Coid, Joseph, Marriott and Tyrer, 2001) and arguably most in need of adult mental health services seem more likely to be achieving transition. On the other hand, it raises concern about what happens to those with other conditions such as emotional problems and neurodevelopmental disorders who also have ongoing need but do not cross the thresholds for transition. Perhaps this is a logical outcomes of successive mental health policy changes which have focused on adult mental health services on meeting the needs of those with severe and enduring mental illness and those who pose the greatest risk to themselves or others (Layard, 2005).

A very interesting finding from TRACK was that actual referrals were significantly more likely to have attended CAMHS with their parents. The Royal College of Paediatrics' *Bridging the Gaps* report (2003) stated that for 10-20 year olds, parents remain key providers of health care. In general, adolescence is a time of changing relationships with parents and emerging independence. Family support may still remain critical for a young person although services, especially AMHS, will need to find the balance between maintaining confidentiality and promoting young person's autonomy with the support and connectedness that a family and carers provide. In addition, while the National CAMHS Review (2008) expresses concern that vulnerable young people, like those Looked After, are more likely to fail at a transfer to AMHS; in TRACK living on their own, Looked After Child status and evidence of Child Protection involvement were demographic predictors of achieving transfer to AMHS.

3.6.5 Optimal or suboptimal transition

A startling, and some might consider shocking, finding of this stage is that only four of the 90 actual referrals (4.4%) experienced an optimal transition. Our criteria for optimal transitions are not particularly onerous or demanding and include: a period of parallel care/joint working, at least one transition planning meeting, good information transfer, and continuity of care (defined as either engaged with AMHS three months post-transition or appropriately discharged). These seem to be part of very basic clinical provision the vast majority of clinicians would agree that everyone undergoing transition should receive. In TRACK, ninety-five percent of young people who made the transition did not receive even these basic standards of care.

Of the only four cases that met these criteria for optimal transition, three had a diagnosis of a serious and enduring mental disorder and had been admitted to hospital at some point while attending CAMHS (two under a section of the MHA). All four were on medication at the time of transition and came from two of the London trusts. Two-thirds of the trusts participating in TRACK, and none in the West Midlands, had a single case who achieved optimal transition. The Department of Health (2006d) document *Transition: Getting It Right for Young People* specifically excludes young people with mental health problems who use CAMHS, citing as reasons the gap in services for 16 and 17 year olds, the development of Early Intervention in Psychosis Teams and examples of good practice

around the country. TRACK findings suggest that optimal transition is highly unlikely between CAMHS and AMHS and 'examples of good practice' are extremely rare indeed. The message is clear: government policy on transitions should not exclude young people with mental health problems; our findings suggest that this is the very group that has suboptimal transition of care. 'Mind how you cross the gap' rather than 'mind the gap' is the more appropriate strap line for CAMHS to AMHS transitions.

Overall, more actual referrals had a continuity of care than any of the other components of optimal transition, which followed in the order: at least one transition planning meeting, then good information transfer, with the smallest proportion experiencing a period of parallel care/joint working between CAMHS and AMHS. About 15% of young people achieved transition to AMHS (actual referrals) despite not having any of the TRACK components of optimal transition. The TRACK definition of optimal transition was based on While *et al's* (2004) direct transition model, i.e. a safe and efficient transfer to adult care, with a focus on continuity of information and cross-boundary and team continuity (Freeman *et al*, 2000). TRACK could have assessed CAMHS to AMHS transition using other transition models, such as the sequential transition model (that recognises young people's changing needs, utilising joint child and adult service provision, focussing on flexible and longitudinal continuity of care) or the developmental transition model (that focuses on developmental continuity, during the process of transition). Although this may have provided different results in relation to optimal transition, given the results on the constituents of TRACK's definition of optimal transitions, and information from Stage 1, i.e. the lack of process addressing service users' and carers' participation in the transition process, better results would seem unlikely.

3.6.6 Predictors of experiencing continuity of care

Continuity of care was less likely for those with emotional/neurotic disorder or an emerging personality disorder. Sub analyses by diagnostic groups or team types were not possible because of small numbers. Interestingly, having parents who were married or cohabiting was a predictor of achieving continuity of care. While it is widely acknowledged that many carers play important parts in the lives of people with mental health problems (Department of Health, Institute of Psychiatry and Rethink, 2006), having parents who are married or cohabiting seems to relate to more than just having a carer. The Cabinet Office's strategy of *Think Family* (2007) also acknowledges the importance of family but does not necessarily promote the 'two parent' model. However, the Institute for Public Policy Research report *Freedom's Orphans: Raising Youth in a Changing World* (Margo, Dixon, Pearce and Reed, 2006) confirmed that children from 'two-parent' families have better outcomes in several health and social domains. Perhaps marital status of parents in TRACK is a proxy for greater or more supportive involvement, or the lack of such a family unit is a marker for broader social adversity. It is certainly an intriguing area for future research. At this stage, we are unsure of the significance and/or the implications of this particular finding.

In conclusion, findings from Stage 2 of TRACK can be summarised as follows: AMHS accept most referrals from CAMHS, even though there is a perception that they do not; in many cases CAMHS do not make referrals to AMHS because of this misperception; despite repeated efforts on the part of AMHS, almost a fifth of service users referred to and accepted by AMHS are discharged without ever being seen; and less than five per cent of cases transferred to CAMHS experience optimum transition. So while transfer of care from CAMHS to AMHS does occur in most cases, good transition of care does not. Enduring mental illness severe enough to require admission to hospital and being on medication are the factors most likely to predict making a transition to AMHS. Continuity of care, i.e. being engaged with AMHS following transfer, is not predicted by these factors but instead is associated with having parents who are married or cohabiting. Those with emotional/neurotic and neurodevelopmental disorders are least likely to achieve transfer to AMHS; and the former are least likely to achieve continuity of care. These groups seem doubly disadvantaged group in transitions. They are the most likely group to fall through the CAMHS-AMHS gap.

4 Stage 3: Organisational perspectives of health and social care professionals and representatives of voluntary organisations

'...it's sometimes said from the adult services that CAMHS transfers are quite difficult because they've been pampered by CAMHS services... it's said in a bit of a negative way and I think it just means that they get so much support at CAMHS and so much multi-disciplinary support that maybe the care co-ordinators in the adult teams feel a wee bit inadequate by comparison ... definitely CAMHS transfers that come to us are really disappointed by what we can offer and can get really upset initially because they feel their needs aren't being met..... not just in terms of mental health care but in terms of helping with maybe education and employment and benefits and housing as well, because a lot of them were on the cusp of moving out of family homes into independent living or supported accommodation. I think a lot feel quite hard done by and feel that if they'd stayed at CAMHS they may have got a lot more support on those things. I don't know if we particularly have a good reputation with CAMHS transfers to be honest.' – AMHS key-worker

4.1 Aims

Stage 3 of the TRACK study aimed to identify the organisational factors which facilitate or impede effective transition of service users from child and adolescent mental health services (CAMHS) to adult mental health services (AMHS). Within this, specific objectives were as follows:

- to conduct a diagnostic analysis across organisational boundaries and services within NHS Mental Health trusts and voluntary organisations by integrating and triangulating the findings of all stages of TRACK (see section 6);
- to evaluate the organisational cultures, structures, processes and resources which could influence the transition from CAMHS to AMHS care;
- to identify specific organisational factors which constitute barriers and facilitators to transition and continuity of care;
- to make recommendations for changes in services, role development, organisational and team practices which could improve user and carer experiences of transition and experienced continuity of care.

4.2 Design and Methods

4.2.1 Diagnostic analysis

Diagnostic analysis is an approach extensively used in organisational research, intended to identify the complexities of an organisation which may frustrate or facilitate the uptake of changes in service delivery and which utilizes mixed methods (NHS Centre for Reviews and Dissemination, 1999). For the purposes of the Stage 3 component of TRACK, the intention was to conduct semi-structured interviews with health and social care professionals and those working in voluntary organisations (n=40) and to triangulate the interview findings with those from other stages of TRACK. The integrated, triangulated findings constituting a diagnostic analysis are presented in section 6 of this report. In-depth findings from the semi-structured interviews are presented below.

4.2.2 Semi-structured interviews

Sample

The original intent was to conduct semi-structured interviews (total n=40) with a purposive sample of key professional staff working in CAMHS (n=10), AMHS (n=10), Social Services (n=10) and representatives of voluntary

organisations (n=10). Following considerable difficulties with recruitment to this stage of TRACK (see section 4.2.3 *Protocol amendments*), a total of thirty-four interviews were conducted with an opportunistic sample derived from NHS trusts in London, the Midlands and voluntary sector organisations (Table 18) below. Sample descriptors by service sector and professional groups are summarized in Table 19 below. Social Services were integrated within CAMHS and AMHS teams in the organisations represented by the sample; thus, social workers are defined as a separate professional group. One participant with a professional social work background fulfilled the role of a 'transition worker' and has been included within the social worker grouping. One service manager had a combined role as a psychiatrist and three managers were responsible for both CAMHS and AMHS.

Table 18. Sample: descriptors by sector and geographical location (n)

Geographic area	Statutory sector	Voluntary sector	Total (n)
London	20	2	22
Midlands	10	2	12
Total (n)	30	4	34

Table 19. Sample: descriptors by service sectors and professional group (n)

	Nurse	Social Workers	Psychiatrists	Psychologists	Service Managers	Other sector	Total (n)
CAMHS	5	3	4	2	2	-	16
AMHS	3	4	2	-	2*	-	11
CAMHS & AMHS	-	-	-	-	3	-	3
Voluntary sector	-	-	-	-	-	4	4
Total (n)	8	7	6	2	7	4	34

*One service manager had a combined role as a psychiatrist, not included in the psychiatrist professional group.

In terms of sector representation by geographical location (Table 18) participants from trusts in the Midlands were under-represented; CAMHS were more strongly represented and psychologists were under represented (Table 19).

Interview schedule

A semi-structured interview schedule was developed (Appendix 4). Questions focused on factors which could impact on transition and continuity of care, including communication within and across organisational

boundaries and with users/carers; approaches to teamwork and decision making within and across organisations; resources to promote transition and continuity (information transfer, staff skill mix and turnover, caseloads/workloads; referral and support facilities); role development, skills and training required to enhance staff confidence in provision of effective transition and continuity to users and carers. Interviews of 40-60 minutes duration were conducted by telephone, arranged at a time convenient to the participant. Interviews were audio-recorded and transcriptions were independently checked for accuracy prior to analysis.

Data analysis

The main purpose of the interview analysis was to identify key organisational cultures, processes, structures and resources perceived as impacting transition from CAMHS to AMHS, whether positively (facilitators) or negatively (barriers).

Qualitative data analysis was conducted using a structured thematic approach (Ritchie and Spencer, 1994) to systematically code, classify and organise interview content into key themes. Transcripts were read repeatedly by RB to identify recurring concepts and categories. These, together with issues incorporated within the interview topic guide, formed the basis of a conceptual thematic framework. This framework was used to code and classify data and modified and refined (by RB) throughout the analysis to reflect the content and issues expressed by respondents across the whole dataset. These coded categories and themes were then sorted and grouped into broader or higher-order themes (core themes) based on similarity of content.

Transcripts were imported to QSR Nu*Dist v.6.0 software to assist systematic and consistent coding and to identify patterns within the data suggesting possible differences in perceptions between Trusts, professional groups and/or CAMHS/AMHS. Illustrative quotes are provided to aid transparency of categorisation and theme representation. To protect anonymity, respondents are identified using a randomly assigned three digit number, professional group and whether working in CAMHS or AMHS. Trust is not identified due to small numbers within some professional groups. A final outcome of the thematic analysis was the identification of four core and nineteen sub themes.

Protocol amendments

Between July and December 2006, ethics and clinical governance approval was obtained to complete the Stage 3 research in all participating NHS trusts in London and the Midlands. Subsequently, key stakeholders were contacted to inform them of this component of TRACK. Presentations were made in a number of trusts to disseminate information relating to the organisational component of TRACK and future opportunities for participation. The original intent was to complete Stage 3 of TRACK within the 6 month period for which funding had been secured as summarized below:

January 2007: pilot fieldwork completed to inform purposive sampling framework and design of the interview schedule; recruitment commenced

February – April 2007: interviews completed

May - June 2007: data analysis and summary report completed.

Considerable difficulties were encountered in recruitment to this component of TRACK, notably in the NHS trusts in the Midlands which is under represented in the final sample. Two Midland trusts did not respond and in those which did, few responses were obtained. In an effort to increase participation, researchers sent three follow-up mailings of invitations to participate to all professional groups within the services/trusts which had expressed an interest in taking part followed up by a telephone call. Intervention by the principal investigator and research ethics/governance leads produced a small positive response. The data collection period was extended to April 2008 to enable thirty-four interviews to be completed, beyond the timescale for funding. Major organisational and service restructuring was in progress in the Midlands trusts which had resulted in service disruption and uncertainty throughout the data collection period, which explained in part the poor recruitment. Similar problems were encountered with the participation of representatives of voluntary organisations, where substantial delays in responses to invitations to take part occurred; reasons for this appeared to be due in part to understaffing.

4.3 Results

Four core themes and nineteen sub-themes impacting on transition from CAMHS to AMHS emerged from the thematic analysis of interview data as summarized below:

Resources

- (i) Adult service workloads
- (ii) Adult services not meeting needs beyond psychosis
- (iii) Learning difficulties, Attention Deficit Hyperactivity Disorder, Asperger's Syndrome, Autistic Spectrum Disorders
- (iv) Lack of specific adolescent resources
- (v) Substance misuse
- (vi) Crisis and out of hours working

Eligibility issues

- (i) Lack of clarity on service availability and eligibility criteria
- (ii) Different thresholds and eligibility criteria between CAMHS and AMHS.

- (iii) Adult services not accepting patients until 17th/18th birthday
- (iv) Variability in service cut off ages

Communication and working practices

- (i) Two way communication and feedback
- (ii) Early communication
- (iii) Joint working and liaison
- (iv) Staff having worked in adult services prior to CAMHS
- (v) Inter-agency working practices and experiences
- (vi) Service user preparation for transition

Service cultures

- (i) Adult services lack of confidence with young people
- (ii) Individual versus family approaches
- (iii) Impact of transition on parents and carers

4.3.1 Resources

Participants highlighted six sub-themes in relation to resources: adult service workloads and inadequate staffing levels; adult services not currently meeting young peoples' needs beyond psychosis; a lack of provision for a range of learning difficulties, including Attention Deficit Hyperactivity Disorder, and Autistic Spectrum Disorders (including Asperger's Syndrome); a lack of adolescent-specific resources, both in inpatient care and community-based; lack of resources in substance misuse and crisis/out of hours working.

(i) Adult service workloads

One of the main barriers to transition put forward by both CAMHS and AMHS staff was high caseloads, due to a lack of adequate staffing levels to meet the demand for adult mental health services. Causes of low staffing levels were not identified, but perceptions were that smaller case loads would help to ameliorate the working situation in AMHS.

'I just think that they're very, very busy and overworked and under-staffed and they just aren't interested in doing anything extra.' (011, Nurse, CAMHS)

'If we had smaller case loads I do think that would help. We have case loads around the high twenties now...' (006, Nurse, AMHS)

Some 'Early Intervention Services' had smaller case loads than more general CMHTs although these also struggled to cope with demand due to lack of staff, which were substantially below recommendations in service

frameworks and policy implementation guides. The impact of demand exceeding resource were lengthy waiting lists for referrals from CAMHS and, in an attempt to accelerate the process, instigation of simultaneous dual referral to both Early Intervention services and CMHTs.

'I don't know what the CMHT case loads are now but I think they're around 20/25 and ours are 15 maximum.' (015, Psychologist, AMHS)

'We are about a third the size we should be for the population we cover in terms of the National Service Framework and the implementation guide; we are still a small team. Consequently we have quite an extensive waiting list which isn't ideal for an early intervention service. That causes problems across the board because the aim of the team is to get involved as quickly as possible and it causes particular problems with referrals from CAMHS. Unfortunately what is increasingly happening is that they will refer to us and they will also refer to a CMHT who will get involved whilst they are waiting for us so I would have to say it is far from ideal at the moment.' (018, Social Worker, AMHS)

Staff shortages and high caseloads created barriers to transition from CAMHS to AMHS. Efforts to cope with staff shortages had led to a rigid interpretation of eligibility criteria and staff with the necessary skills to work with particular individuals might not always be used effectively when workload and time pressures were present:

'The more swamped we become, the more rigid we get, we apply our criteria much more rigidly and there is much more pressure on us to move people on at the end of their three years with us so it has a knock on effect all the way through.' (018, Social Worker, AMHS)

'I think sometimes we underestimate the skills of our own staff who are quite busy but if they had a bit more time to work with individuals they would actually be able to do some of the work that we are farming out to other people.' (006, Nurse, AMHS)

This could lead to shifting 'knock on' pressures to other parts of the service as well as having implications for staff training and development. This potential for shifting pressures to other parts of the service also had longer-term resource implications. Young people who failed to transfer smoothly from CAMHS were likely to re-engage with adult services on an unplanned basis, at future crisis points in their lives:

'That lack of people then results in a threshold being placed at a higher level, or being less able to engage with work within adult services for young people with a relatively low level of need, but from the young person's perspective that might be very important to them in preventing them from needing further help down the line at points of crisis, which is what we would routinely experience, that young people keep coming back through the system at points of crisis through self-harm, substance misuse, difficulties, other factors bring them in. And if we could engage with them more proactively at the front end, on terms that are more acceptable to them, that would be an important part of resourcing.' (030, Psychologist, CAMHS)

(ii) Adult services not meeting needs beyond psychosis

In addition to inadequate staffing and caseload pressures within existing AMHS, participants highlighted a range of resource gaps in terms of types of service provision, notably the narrower range of service provision in AMHS. As a consequence of narrower ranges of service provision, concerns were expressed that needs of individuals, with the exception of those with diagnoses of severe enduring illness (e. g psychosis), were not being met.

'The big problem is the CAMHS services available are broader than the services in AMHS. So, there are some young people where there is really nowhere to transfer them to.' (026, Trust Manager)

'I think that certainly the criteria are really so tight that it only meets the needs of a very small group of chronic and enduring illness.' (005, Psychiatrist, CAMHS)

'...the problem with the adult transferral services is that we actually find it nearly impossible to transfer anything else except psychosis – it's complicated when you have anything combined with depression, it's really impossible to transfer...' (016, Psychiatrist, CAMHS)

The range of needs identified included those resulting from emotional difficulties and emerging personality disorders (for which demand was increasing) which did not always fit with criteria for referral to AMHS within the definitions of mental illness which were applied:

'We see lots of young people who have emotional difficulties, where you may not be able to say they have a clear cut depressive disorders or anxiety disorders, but they have emotional difficulties. They haven't got developmental disorders, they're not psychotic, they don't have an eating disorder, but they do have a mental health need and there is no neat dovetailing.' (010, Psychiatrist, CAMHS)

'And the other group is the people who are self-harming and who are, in a sense, emerging personality disorders. I think they're becoming a much bigger group. They don't meet the criteria for adult services because they don't have a diagnosis of a mental illness.' (026, Trust Manager)

Where transfer to adult services was either not possible or appropriate, participants described several ways of managing such cases. One approach was that young people might be left with CAMHS for as long as possible. Clearly, there were resource implications for CAMHS in keeping young people beyond an appropriate transfer point and it was also acknowledged that the needs of some might not be met within alternative areas of statutory social services. In the view of respondents, this had implications for commissioners of services.

'So the CAMHS service is left holding that population and so there is quite a sort of significant commissioning issue about service gaps with that group as an example.' (019, Trust Manager)

'We either keep young people on longer than we should. Others might get some service from local authority social care. So, you might be relying on another agency. But their aims might be different, so you wouldn't expect them to pick up the whole range of need. So, there are some young people for whom their needs will simply not be met.' (026, Trust Manager)

Alternatives, where individuals did not meet the various statutory service criteria described, were either return to the care of a GP which could necessitate dialogue where they were not disposed to prescribe treatments, or, in some trusts, signposting to the voluntary services sector, particularly counselling services, where these were known to be available and appropriate. Again, the situation could arise where CAMHS continued to retain the young people involved (see also p 93):

'I mean if somebody didn't meet the criteria of either of those services, I mean the only thing that we really have to offer is to go back to the GP.' (011, Nurse, CAMHS)

'So we would have to go into dialogue with our GPs who are also reluctant to prescribe for it, to find an ongoing treatment. So in some cases we might end up holding onto children until they reach early adulthood, which is not ideal.' (024, Trust Manager)

'There are a few in this area. [Named organisation] is a very good counselling service locally.' (003, Social Worker, CAMHS)

However, voluntary service participants said that some young people with early onset psychosis were still 'falling through the net' because some CAMHS tended not to work with this diagnosis and the consequence could be admission to acute adult services. Concerns were also expressed about young people with severe and enduring mental illness requiring support, which if not provided could result in serious problems in the longer term.

'Because CAMHS tend not to work with people who are psychotic, so the only alternative for those people who do have those problems is to end up in adult services. That may even mean having an inpatient stay in places that are age inappropriate... Where it would tend to come to our attention will be if someone is 17 1/2 and has ended up on an adult ward.' (032, Voluntary Sector)

'Our team by definition takes people needing longer term support. Automatically we look for clients who've had a diagnosis and have been with other teams for a long time and they've not been able to discharge them, so our threshold criteria is quite high as a result of that. It could be a possible barrier for people who do not meet our criteria if they have mental health problems which, if not addressed, could develop into more severe difficulties longer term.' (034, Social Worker, CAMHS)

(iii) Learning difficulties/Attention Deficit Hyperactivity Disorder/Autistic Spectrum Disorders

The most frequently mentioned resource gap by all groups of professionals in all Trusts and by non-statutory organisations, concerned a lack of adult

service provision for young people with developmental disorders, particularly Attention Deficit Hyperactivity Disorder (ADHD) and Autistic Spectrum Disorders (ASD) including Asperger's Syndrome. It was seen as a growing area of demand by psychiatrists and representatives of voluntary organisations as exerting a negative impact on transition.

'So there is quite a significant group of people with developmental disorders, e.g. ADHD. There is no elaborated service for such individuals across the divide or indeed a description of such services within the Trust.' (004, Psychiatrist, AMHS)

'I despair really, it's the only time I do despair because there isn't a clear Adult Service that we can refer to...' (020, Nurse, CAMHS)

One psychiatrist and representative of a voluntary organisation estimated demand as approximately half of those on case books after the age of 16 years. The impact of lack of service provision resulted in some young people travelling significant distances to access voluntary sector support groups:

'We have around in between 350 and 400 cases of ADHD and with that population 50% of them will have had ADHD after the age of 16, you can calculate the numbers, though having said that some of the kids they might benefit from medication actually they stop medication of their own accord around that time because they don't want to be medicated, so I would say that in between 30% & 40% of that number, it would be good if there was a service to be provided.' (016, Psychiatrist, CAMHS)

'We have a core group of regulars and a number of people who dip in and out. We've had about 50 or 60 over the last couple of years. We've had people coming from [named conurbation] which is a good thirty miles away because there's nothing there either.' (028, Voluntary Sector)

Some Trusts were actively considering how best to meet this growing need and the positive factor here was that the lack of services had been identified and was being addressed. Approaches were to address the problem, most likely within the context of primary care, following discussions with commissioners of services. In contrast, other trusts were actively developing services for young people with and adults with ADHD learning disability, noting the need for AMHS professionals to develop skills to manage these individuals.

'It may be that they won't be met in specialist secondary sources. It may be that they need to be met in primary care and what's needed is more of support and maintenance function rather than an intervention function. I don't know. What I do feel is we jointly need to do some work on that with our commissioners.' (002, Trust Manager)

'We're currently developing services with children with learning disability which is something that wasn't provided as well as we could have. Also adults with ADHD. Whilst we can treat children with ADHD, we currently don't have the specialist skills in our adult service to treat people with those needs.' (033, Trust Manager)

Some voluntary organisations, formed by parents and carers, were a potential source of expertise in managing disorders such as ADHD. These have largely been formed in response to the fact that statutory services have been unable to meet the growing demand for information and support for families living with a young person with ADHD. While deliberations over future statutory service provision continue, concerns arise over a reported loss of funding for voluntary services providing crucial support to 'desperate' parents looking for help in managing their children's behaviour:

'Until recently we've had funding from the children's fund, which is part of [named part of] Social Care. But we've just lost that funding now, so we're a bit worried. The services were led to believe funding would be ongoing. They did a survey on it last year and found that it was working really well. Because they were getting so many people going to social care desperate for help in managing their children's behaviour that it was supposedly cost effective to provide support for a group. But that's now come to an end. Apparently the funding could be supplied from elsewhere, but when you actually try to get the funding from elsewhere, that's not the case. They fund a room for us once a month to meet as well as providing money for books etc to help educate our parents.' (028, Voluntary Sector)

One view was that the issue with ADHD related needs was a lack of resources in social services that mirrored some of the issues raised with regard to restrictive eligibility criteria within mental health service provision. Another professional warned of the dangers of young people with ADHD who were not taken on by adult mental health or learning disabilities services post CAMHS, finding their way into adult services later through drug and alcohol services:

'...it seems as though partly that's a problem with the level of resources within Social Services and then a wrangle whether someone meets their criteria, someone with a learning disability or whether they meet the criteria of someone with a mental health problem, so I think that's where maybe they fall between two stools and it's strapped services trying to protect their scarce resources.' (003, Social Worker, CAMHS)

'In adult services, those people are often getting more involved with drug and alcohol services and accessing adult services through those.' (021, Nurse, AMHS)

Various options were put forward to resolve some of these issues. One approach was to lower thresholds within learning difficulties services and have specialist input, although this was not without perceived limitations in terms of workload. Other approaches consequent on the experiences highlighted below were to change the criteria or eligibility thresholds for CMHTs to include ADHD and to increase AMHS professionals' skills in dealing with ADHD.

'Ideally I would like learning difficulties to take on things at a lower threshold but ... what could improve it? I think we could probably benefit from more specialist input into the team although I say that with a

reservation because we quite often get a lot of, this is a specialist forensic worker, they are only here for advice or this is a specialist dual diagnosis worker, they are here for advice. Sometimes we have a lot of advice but it doesn't feel to the individual care co-ordinator that they have got a lot of actual support with the work, if you see what I mean. There are lots of people offering advice but nobody actually doing the legwork. If we had smaller case loads I do think that would help...' (006, Nurse, AMHS)

'I had one young person with ADHD. That was a challenge again because there are no adult psychiatrists within (named Trust) who are readily developing a service or accepting that this is their remit when a young person reaches 17. So with this particular young person, I wrote to my counterpart in adult mental health services working in my geographical patch and said, this young person has ADHD, he still has an ongoing need for medication. Guidance recommends consultant supervision with GP prescription in between. Can we think about the transfer? Would you like to come to a clinic? Would you like to meet the family? How would you like to do this? And the initial response was, "I don't have any experience in ADHD, so I can't do this."' (010, Psychiatrist, CAMHS)

Some Trusts had developed transition/link/liaison worker posts focusing on ADHD and learning difficulties which was reported in one case to have worked well but funding had been lost for the post. This participant also went on to say that funding had also been lost for resources to help train adult service workers to be able to take on more young people with disorders like ADHD. Both of these respondent experiences raise issues for commissioners of services and managers prioritising service developments and training needs of staff. Access to CPD by staff is identified as a vital area of career development in current NHS policy:

'...that role was more to think about people with ADD kind of disorders that happens to them, that was very specially trained and then to think about the transfer to adult services but unfortunately the funding for that post has been lost.' (016, Psychiatrist, CAMHS)

'I did ask for extra resources in order to keep them (young people) until the age of 25 and then to have that time to train people in adult services, to help them get trained to provide further service. I think at this point of time we have so much trouble with our cases of ADHD because the number of ADHD just keeps multiplying, so we are working harder with the GP, I'm not talking over 18s, I'm just talking for under 18s, and it's not the priority to think about that, though over a period of time the numbers are going to grow and it is the question for adult services are they going to have adult services for ADHD? Do they want to form something locally?' (016, Psychiatrist, CAMHS)

Voluntary sector participants supported the idea of outreach workers in this area. Some exemplars of good liaison by outreach staff with regard to involvement in addiction units and in local schools, supporting the work of teachers were identified. The point was made that common strategies existed which could be operationalised for both ADHD and autism.

'In this area we have counsellors going into local schools and a very good drug and alcohol unit...' (023, Voluntary Sector)

'Another thing that would help would be having an outreach worker from CAMHS. Somebody who can go into schools and give schools tips on how to manage these children. Because they can be managed, if they're managed in the right way. Especially in primary schools, they have their own places to sit so they're not wandering around. Maybe giving them something to hold in their hands so they're not fiddling. Or they sit in a certain place, their certain place. There are all sorts of different tactics you can use and I don't think all schools employ those strategies. And not all children are the same of course. The [named] Autism Support Service has an outreach worker who goes into schools and helps the class teachers. ADHD needs something like that. Somebody who can offer help to schools in how to manage those children. A lot of strategies you can use for autistic children work with ADHD children too.' (028, Voluntary Sector)

(iv) Lack of adolescent specific resources

Participants identified a lack of adolescent specific resources, both in inpatient care and in the community. With regard to inpatient care, participants reported some Trusts had no inpatient facilities for adolescents or none covering CAMHS geographical areas of responsibility:

'I suppose the most obvious gap for this area is an inpatient facility for CAMHS clients, it is a major issue. If we need to access an inpatient bed for a CAMHS client there are no CAMHS inpatient beds in the area at all. We should really be looking within the organisation at inpatient beds specifically for the age group of say 16 up to maybe 25 so that you are not admitting them into the wide range of the adult population.' (013, Trust Manager, AMHS)

Some participants recognized the difficulties in designing and providing services appropriate to an important but relatively small group, but noted that the consequences could result in increased travel to access services at a geographical distance. Nevertheless, serious environmental, social and emotional concerns remained about admitting young people to adult wards and staff were generally reluctant to admit young people unless absolutely necessary; a need for the provision of interim care facilities was seen to be a solution by one psychiatrist:

'I think there is this issue of appropriate inpatient care for people who are young but relatively unwell. This is always the difficulty in designing services for relatively small numbers of people. There are just not enough numbers of that group of people to design services around. So people end up going to another borough or part of the country because that's where the unit for that particular group of people is. So there's a shortage of appropriate inpatient care.' (032, Voluntary Sector)

'Well, I think there's certainly a need for better residential support. Like interim care facilities. Very often, the last thing you need to do is take a psychotic 16 year old and put them in a room of shrieking, psychotic 25

year olds, it can brutalise them and children especially are sensitive to violent influences. And nursing staff who are accustomed to working with over-18s feel a little bit de-skilled when handling children. We do need to improve the resources for people in crisis, away from the adult mainstream setting for some. Some people are so psychotic of course it doesn't really matter, because the age is irrelevant. For ones where psycho-social variables are far more significant to the form, I think there's room for expansion there.' (014, Psychiatrist, AMHS)

Having properly trained staff, particularly nurses, capable and confident in working with young people has implications for workforce staffing levels, training and development and mirrors issues raised by CAMHS staff with regard to adult counterparts in CMHTs feeling de-skilled when working with children. Adult inpatient wards were described as lacking as lacking in the provision of age appropriate facilities and activities for young people, notably in the area of education and training. Staff in Trusts, both with and without access to age-appropriate facilities, supported the provision of small units, with properly trained staff, separate from adult wards as a solution:

'I think the wards are not appropriate for young people at all. They're barely appropriate for adults to be quite honest, so I don't see them as terribly helpful. Compared to a specialist ward, there's very little going on in the ward, the service like a cup of tea – or nothing really and I think it's an issue for adults, but it's more of an issue for youngsters. That can be a problem. We've got a young person stuck on one of the wards because of sexual abuse at home and it's difficult for them to go home, but while they're on the ward they're kind of being quite seriously wasted, I think, in terms of education and training and age-appropriate activities and all those sort of things that young people should be getting on with.' (015, Psychologist, AMHS)

'Whilst I don't advocate admitting CAMHS clients or clients in transition to inpatient units very often, it is so difficult when you have got a child that can't be managed in the community and it is traumatic for the child, for the parents but also for staff. If we can do anything better it would be about having a small facility for admitting a child where not only could you admit them but you had the staff who were properly trained to look after them. That in itself would probably make transitions better and take some of the mystery out of it.' (013, Trust Manager, AMHS)

In addition to age-appropriate inpatient facilities, respondents stated a need for more community-based resources for young people, with the emphasis on ease of access, non-stigmatization and flexibility to support engagement and pick up of services: Flexibility, particularly, is a key aspect of young peoples' service delivery. Early Intervention services' staff described a flexible approach, particularly in relation to communication, as being a fundamental and vital element in successfully engaging with adolescents:

'People are trying to offer more talking therapies at primary care level and the government clearly wants to expand that and I think that's an excellent idea. The problem is there's a group of young people that won't pick up because they won't go along to a GP's surgery or keep

fixed appointments. You need more walk-in and non stigmatising services. If there were more youth services in the community they could go to talk to somebody. Also places in colleges, like mentors, who could work more flexibly.' (027, Psychiatrist, CAMHS)

'We have quite a flexible approach and we do things with certain clients, we give out our mobile numbers. A lot will find that helpful, so they can make appointments by text, whatever's easiest for them. I think a lot of it is the flexibility and being aware of the young client group of people who have other things to do, they don't just want to see us so we try and fit around that really.' (017, Nurse, AMHS)

(v) Crisis and out of hours services

Participants, particularly but not exclusively in one Trust, expressed concerns about a lack of outside office hours outreach services for young people in crisis. Absence of such services clearly has potentially serious repercussions for individuals' welfare and highlights unresolved issues with short-term organisational mechanisms and practices for coping with temporary and immediate care crises. These include disputes over eligibility criteria, differing service cultures and working practices:

'Out of hours arrangements. CAMHS, under 17, with a difficulty at the weekend, but that doesn't need emergency psychiatric inpatient, which for us is in [named city], there are no services like the crisis intervention team for our young people. They have to be closed to CAMHS to be open for them. So I've had people over 16, open to CAMHS, have a difficulty at the weekend, but managing in the community, there is no one to ring up and say help get them through the weekend. No outreach element to our service. Funding was removed. So we don't have the facility to say we have nursing staff within our own team to come and see them at the weekend.' (010, Psychiatrist, CAMHS)

'I think CAMHS not having their own out of hours crisis team. So I can think of an example of a young person I've been working with who is 17 now and was needing support out of hours, was depressed and using self harm with some suicidal intent but it didn't fit – we liaised with the adult crisis team, this person was presenting at A&E and because she was just under 17 the protocol for young people under 17 is that if they present at A&E because they self harm they get admitted to the paediatric ward. If you are over 17 you get assessed by the adult team. We had already liaised with the adult team because we were aware that there was a high risk of this happening and this young person lived on her own in a housing association flat and it was about trying to get her some support over the weekend, but it didn't quite fit into their kind of model so it was acknowledging that there was a need but she kind of slipped through the net of people's thresholds. They did offer a service but it took a lot of working with and it was very much a holding service until we were back in on the Monday... our on call system means we have a child psychiatrist on call at weekends, there is no on call cover from nine o'clock in the working week until nine o'clock in the morning.' (007, Nurse, CAMHS)

(vi) Substance misuse

Both voluntary sector and CAMHS participants identified support for young people misusing substances as a gap in current mental health resource provision. Specialisation within services was partially blamed for this particular gap arising, which was being resolved through more integrated working between statutory and voluntary sectors. Other respondents identified a need for further training in substance abuse for health professionals.

'Another group is those who are misusing substances. Again, that seems to be quite a grey area.' (032, Voluntary Sector)

'The CAMHS/adults substance misuse and children and families, we are working together, and the voluntary sector, working together very closely to try and make sure that we're filling in some of the gaps that have arisen over the years and that specialisation has taken place.' (022, Trust Manager)

4.3.2 Eligibility issues

Professionals described four sub-themes regarding young people's eligibility for particular services: a need for greater clarity, information and understanding of what is actually available to CAMHS staff looking to providing ongoing care; recognition and concern over differing thresholds and eligibility criteria between CAMHS and adult services; adult services not accepting patients until their 17th or 18th birthdate and; variability in service cut-off ages.

(i) Lack of clarity on service availability and eligibility criteria

Professionals within CAMHS and AMHS called for greater clarity, information and understanding of adult service availability and eligibility criteria, to inform and enable CAMHS workers to transfer a young person to adult services. More specifically, adult service workers navigating children's services also needed greater clarity in terms of roles, responsibilities and the scope of children's services, which had a broader coverage than mental health alone and included education and youth offenders. Also, selected social services (e.g child protection) were in some areas managed and delivered separately from mental health services, rather than being integrated within adult CMHTs alongside other aspects of social care. This call for greater cross boundary information and understanding included voluntary sector services availability and expertise:

'Clarity over what's expected of adult services would be helpful. There is a great deal of ignorance on the part of CAMHS as to what adult services do or might do, particularly for some of the more difficult cases, for example ADHD or ASD. The range of things adult services do. Youth offenders are a morbidly disturbed group of people, but we don't have a mandatory remit for their issues. We tend to be the first port of call from CAMHS even when there is a drug issue.' (004, Psychiatrist, AMHS)

'It does seem a bit vague to me what's available.' (020, Nurse, CAMHS)

Confusion could also be exacerbated for some services, for example, Early Intervention teams, operating in more than one geographical area. This lack of clarity and resulting confusion also impacted negatively on service users both directly and indirectly:

'If anything it is possibly more complex in (named geographical areas) because they seem less clear who we are, so even if they might understand the structure of a CMHT, we're even more peculiar really in that we cover all (geographical areas), we're called something different, we're located in (named geographical area) so I think we are confused with the mental health services.' (018, Social Worker, AMHS)

'...so the clarity over transfer by the team would help a lot and would help the service that is given to the young people because they are confused. They don't know who they should be making contact with.' (008, Social Worker, CAMHS)

'I think it is quite hard sometimes for our workers to know who does what because there are Children in Need teams, there are Child Protection teams in the local authority, there's Looked After Children teams, there's a CAMHS team – you know, there are various children's services that as a adult worker nowadays it is quite hard, especially as most of our workers haven't ever had child protection experience or child care experience at all, I think they find it quite hard to navigate their way round the system and try and work out what does the Looked After Children team do that is different to the CAMHS team and some people are worked with by both teams and some are ... it is very confusing I'd say. Who does what at what stage, who carries on till 21, those kind of things.' (006, Nurse, AMHS)

(ii) Different thresholds and eligibility criteria between CAMHS and AMHS

Both CAMHS and AMHS staff perceived that CAMHS tended to work with a different client group in terms of the nature of a young person's presenting problems, with CAMHS becoming involved at much lower thresholds than adult services. The lack of AMHS provision for children who have emotional and relationship problems and who self harm was raised again in this context. Other respondents cited examples of age interpretation impacting on early transfer of young people with psychosis and others noted that the presentation of a diagnosis of psychosis in crisis did not always ensure transfer to AMHS.

'It feels sometimes the adult mental health service has a very medical, biological model so of course there is going to be a discrepancy between young people who are perhaps 16, self harming, have low mood, relationship difficulties, poor self esteem, who don't have problem solving skills, that meet the threshold with those things being a combination for CAMHS but aren't going to meet the threshold for adult services or adult mental health services.' (007, Nurse, CAMHS)

'I think one of the difficulties is that – and how can I put it politely – I think what our thresholds would be for being involved in a young person's care and treatment and thresholds for Adult Services are very

different. That's certainly the conclusion I've come to in recent episode of psychosis and even that can be open to some interpretation because we've just had a young woman recently who's being trying to transfer to (named geographical area) and she's had two episodes but she's still only 15 and has been with the First Episode Team and they said well, sticking very rigidly to the interpretation of first episode, they said no, she's had a first episode treatment, she needs to go into Adult Services, full stop, and it really is very disturbing a 15/16 year old being shoved into Adult Services.' (005, Psychiatrist, CAMHS)

'Maybe the CMHT will take her on but I'm not sure. They have a slightly higher threshold for involvement than we have in terms of clients being in crisis.' (015, Psychologist, AMHS)

Also, respondents expressed concern over being unable to transfer young people during periods of wellness and relative stability, despite those often being the best times for them to cope with the potential stresses of transfer. Again, these illustrate the tension between short-term, operational thinking and what is in the young person's longer-term interests. Contact, once lost, is notoriously difficult to re-establish. Resurgence at crisis points in adulthood has case management and unplanned resource implications for service providers as well as potentially highly damaging personal consequences for young people beyond the transition phase.

'Also a lot of the time you're wanting transfer with people who have been through a treatment phase where they're actually quite stable, engaging reasonably well, complying with medication, going to college or starting and happy with wherever they are. Then the adult teams say, they are low priority for us. We feel that if they don't pick them up, sustain them, then the chances of them relapsing is quite great. It's a shame because the adult teams don't feel they have the luxury to do that. Their work is with people who are less able to engage, needing inpatient admission, have possible forensic histories, severe social histories rather than people who are well settled and treatment compliant.' (031, Social Worker, CAMHS)

(iii) Adult services not accepting patients until 17th or 18th birthday

CAMHS staff felt adult services were often very rigid with regard to age criteria when transferring young people. The quotations below clearly demonstrate that this is a form of protectionism for adult services staff, who, as identified earlier, already have high caseloads and not always enough trained staff to meet demand. Short-term priorities therefore appeared to override existing transition protocols which allowed for, in most cases, a six month handover period.

'Their criteria is 18 and they'll go from 18. It's just a very rigid interpretation because it protects them. Some of the adolescents we transfer to them have been very, very difficult as well – they're just trying to put off allocating until the last minute. I've had experiences with the adult teams where I've phoned up a month before somebody's 18th and they won't even set a CPA date – they say, no ring us back once

they're 18 and I've said but the policy's not that – so it's in the face of, I don't actually think it's worth the hassle, it's easier just to go a bit later when they're more likely to respond to you.' (011, Nurse, CAMHS)

'I think it would probably be fair to say that the perception from CAMHS would be that you had to wait up until the 18th birthday... I think for us the bits that are quite difficult is that CAMHS want us to be involved earlier and I have to say we would bat it off a bit. We know we are going to get it but it is one of a number of things that are knocking at our door so we tend to think, there is part of us that thinks well they have actually got a worker at the moment, we know we need to take them on but they are safe. I wouldn't be surprised if from the other end it felt like a bit of wrangling at the early stages, but once a worker has been identified, then I think the process is relatively straightforward depending on what they are doing.' (006, Nurse, AMHS)

Participants also drew parallels with rigid operational age-based distinctions made between 'adult' and 'older people'; the need to allow individual merits of a case to inform decision making was emphasized alongside a need to avoid people being transferred around the system due to lack of perceived accountability.

'You see the same thing at the other end of the scale when you're trying to hand on patients to the other services – if a patient's been receiving medication and good domestic/community support through a chronic schizophrenic illness, why the hell should you have to change the case manager on their 65th birthday? Everything else is the same and it's just that 20 seconds ago you were 64 and now on the stroke of midnight you're 65! It's silly. And the same logic applies at the other end. You go on the individual merits of the case and any other thing, any attempt to do otherwise is inhumane and unprofessional.' (014, Psychiatrist, AMHS)

'This distinction between being in CAMHS or adult services or old age services, I don't know that that's helpful. We don't see it as being flexible. We see people being bounced from one bit to another, with everyone trying to claim it's someone else's responsibility.' (032, Voluntary Sector)

One participant said they were starting to see some improvements in one Trust, but only after reminders of the existence of a transition protocol. No mention was made here of the existence of integrated care pathways. This response raised questions about approaches which had been used to develop and implement protocols and their perceived utility in practice:

'There is a transition protocol which is out of date and is being reviewed, so that might have been part of it. Sometimes you can't even get past the CMHT secretary if the young person isn't 18. So we had to remind them that there was a protocol and it was as relevant to them to abide by as us, but some people didn't see it. So, over time, there's been a little bit more pressure on people in the Trust to get more involved and

perhaps attend a CPA meeting before the young person's 18th birthday.'
(021, Nurse, AMHS)

(iv) Variability in service cut-off ages

Many staff referred to the wide variability in service cut off ages impacting decisions on where to transfer young people, resulting in a need to work across service boundaries where shared care might be required:

'Social Services have often withdrawn before somebody's 18, so they're often not around at the time of transfer – it's very hard to get anything from Social Services once somebody's over 16 unless you're looking at supported accommodation and then they have a 16+ team to cover that kind of thing and look at support around that.' (011, Nurse, CAMHS)

'Transition to adult services, we see young people up to the age of 14. If they are engaged in long-term treatment, then we would go beyond that age. Ordinarily, anyone over the age of 14 goes on to the adolescent service, so we wouldn't get referrals over 14. The adolescent service goes up to 21. Substance misuse goes up to 21.' (001, Nurse, CAMHS)

In some cases CAMHS deliberately continued working with a young person after the service's upper age limit has been reached if they saw a definite reason for doing so. In contrast, other agencies, particularly the non-statutory sector, worked with much broader age ranges:

'I think we sometimes continue working over the age of 18 and that's kind of in the cases where there is specific piece of work to be finished or for the cases of people who are in long-term psychotherapy. I think we will continue working with them until their 19th birthday or until they then go to University. In an ideal world, the transition should not be made at 18, they should at least be 21 or 25.' (016, Psychiatrist, CAMHS)

'There's Connections who have been helpful in terms of – they will take our clients of up to 23 I think, because they accept that they're vulnerable and therefore the normal age cut-off doesn't apply.' (015, Psychologist, AMHS)

There was, however, recognition throughout services that finding an appropriate age range was difficult, since current age limits may be arbitrary and defined partly by legislation. Others also acknowledged the difference between legal designations of adulthood and service user maturity, which impacted on a young person's ability to engage proactively with adult services. This was particularly relevant for young people with learning disabilities:

'I think we're to some degree governed by children's legislation because people looking after children need to have specific training in looking after children and every child matters. So, I think there's some specific issues there, but beyond that we need to draw a line between child and adult services and it may be an arbitrary line, but 18 is as good a line as any. It's a blunt instrument and it's not needs led, but that's where we are.' (033, Trust Manager)

'16-18 is a difficult banding. Within that frame, then the issue relates to educational circumstances, traditionally. If you're in full-time education, the referral is into CAMHS. If you're not in education, you're in employment; the referral is into adult services. There then becomes a tension, because between 16-18, there's something about the appropriateness and the intellectual appropriateness of the individual as to how they would respond within the service and the environment.'
(002, Trust Manager)

'I think there's a lot more to be done in changing the mindset of the adult teams. But a lot of the young people with learning disabilities mature at a later age and are not able to say what they want...' (031, Social Worker, CAMHS)

4.3.3 Communication and working practices

This theme concerns communication, feedback and working practices between CAMHS and AMHS, interagency and with service users and their families in preparing them for transition. Unlike the other themes, participants expressed very mixed views. Some described highly challenging and sometimes fraught experiences, particularly in working with other agencies, while others highlighted more positive progress, successes and areas of good practice.

The sub-themes concern: communication and feedback processes; positive aspects of joint working and liaison between services; staff having worked in adult services prior to CAMHS; interagency working practices and; service user and families preparation for transition.

i) Communication and feedback processes

CAMHS workers particularly described a lack of two-way communication with adult services as a challenge affecting transitions:

'The impact of parenting on the family is very important and we try to make sure adult services are aware of particular issues, but it doesn't seem to work the other way with us. In fact, I can't think of any instance where we have been told, this person is known to us or where we have been contacted by someone in adult services working with somebody where they know there are young children involved.' (001, Nurse, CAMHS)

'There is a lack of communications, nobody comes back to you and says I've not received this or I've not received that until sometimes afterwards and sometimes it's the case where you have to chase up with them.'
(008, Social Worker, CAMHS)

The same participant explained that often administrators and gatekeepers to CMHTs are not co-located with the rest of the team, hindering effective communication. Where communication was reciprocal it was perceived as facilitating transition, particularly when different parts of the service had different record keeping systems:

'That has been my experience and you get the team administrator who might not be in the same office as that person so can't even tell you where that person is or what time they are going to be back and so these are the bits and pieces that you need to find out, whether there are any queries that you might have, they are a lot more difficult when you are not able to speak to that person or even know where that person is so you can call back at a later time.' (030, Psychologist, CAMHS)

'I think it would probably be around communication, that all the workers involved have good communication and because we both keep notes very differently it is making sure that those, that kind of paperwork, goes with the service user because we do read past stuff and it is useful to have that as a back up because some people get really angry when they have to keep retelling their story so I think it is about communication and about having an understanding of one another's services I think.' (009, Nurse, AMHS)

Another related challenge was seen as inconsistent documentation, particularly with regard to care planning (CPA). Different electronic record keeping systems was cited as partly responsible, but also a lack of understanding of CPA processes more generally:

'One quite big thing that's come up for us is documentation because I think general adult teams and specialists have been running with computers and with the system XXXX for a long time and we've had to do CPAs for a long time and on the system, whereas with CAMHS it just doesn't seem very consistent and their understanding of who should be on enhanced CPA for instance can be quite different to ours, so things like that can be a bit tricky at times...' (017, Nurse, AMHS)

Communication around referrals was seen as a particularly challenging area. Some Trusts have a central referral point for adult mental health. Respondents in these trusts perceived both benefits and disadvantages of having central referral systems. Benefits included greater responsiveness and less focus on eligibility criteria in decision-making. Disadvantages concerned lack of dialogue between individuals and services about cases:

'I think the adult mental health service in the main are pretty responsive and I find they rarely quibble for example about referrals. In the main if we make a referral they say yes, absolutely, we'll allocate that or pop that on a waiting list, so they are fairly streamlined. Now that has its advantages but actually it also has some disadvantages because one never then engages in a dialogue with anyone about the case but I don't think it is as frustrating as it might be.' (012, Psychologist, CAMHS)

Some participants noted communication around referrals was often quicker when approaching adult community mental health teams rather than contacting consultants directly:

'I think it depends which team you write to or whether it's the consultant or the community team. I've found the community team is better at responding than the consultant themselves.' (029, Nurse, CAMHS)

Participants stressed the need for and benefits of early communication with regard to smooth and effective transition. This allowed more time for the young person and their families to adjust to coming changes; the importance of not leaving it too late to commence transition was emphasized.

'I think it was early communication, it was having clarity about what we were asking for and for some people it was a referral letter, that was as great as the involvement was, a referral letter and asking for the adult team's consideration or opinion. For other people I can foresee that this is going to be difficult and will be consultation work, so I think about whether it is going to be an appropriate referral and how it is best managed but it is about trying to bring services in as early as possible to do the thinking.' (007, Nurse, CAMHS)

'Again from a personal clinical point of view I think often we leave it too late, we wait until somebody is 17½ and say right, now we need to do transition. If someone has been in service longer it is something we should start thinking about early on to allow not only the client but to allow the family to build up new relations with new members of staff.' (013, Trust Manager, AMHS)

Staff also referred to the importance of sharing information by all concerned in transition was emphasized, together with importance of transparency on risks and care planning at handovers between professionals. These benefits of early communication and sharing information can, however, often be cancelled out or negated by impeding pressures already described where high workforce workloads exist and eligibility criteria rigidly interpreted, particularly those relating to non acceptance of referrals or case discussions until a young person officially reaches a service minimum date of acceptance.

'A shared set of symbols and assumptions, shared by the patient as well as the people on both ends of the giving and handing over. Of course, those assumptions also include shared notions of risks. If someone tried selling me little Barry and they had polished him and shone him as a really nice, sweet little kid who stopped taking drugs ages ago, and the word drugs isn't specified and they don't tell you that Barry has just come out Borstal after stabbing his dealer, and actually he's got a snort of cocaine in his pipe every night kind of thing, that is not going to go down so well. You need to share risks clearly as part of the treatment plan.' (014, Psychiatrist, AMHS)

ii) Joint working and liaison

Staff in one Trust described the benefits of having joint posts between CAMHS and adult mental health service teams, in this instance the early intervention team. However, events had resulted in subsequent loss of the post with a negative impact on patients with regard to transfer.

'Two years ago we had a post, which was a joint post with the (early intervention team) and that job worked really well because the person belonged to both teams and transferring the patient from our service was

taken much earlier and then transferring them seamlessly and staying with their Care Co-ordinator once transferred to the other part earlier on the psychosis service, so that worked beautifully and then somebody left and it took us 14 months to renegotiate with adult services because they were restructuring, having lost money, redeployment, and everything else and the cuts... so there was a huge delay... The strength was the joint post, definitely. It was smoother, quicker, efficient, because what happens now without that post is that the patient does not want to go to adult services so we have a lot of resistance, patient resistance about transfer.' (016, Psychiatrist, CAMHS)

'...it was certainly better when we had a transition worker here who crossed the two teams... if they fit the criteria and they accept them, then the transition is easier, I would say, almost seamless.' (020, Nurse, CAMHS)

For cases outside the early intervention remit, benefits of joint posts and transition work were cited. One participant felt it was important for an individual with a joint post to maintain a small caseload for internal team credibility:

'...identifying which team needs to be referred to and liaising to make sure the case is picked up and support the process through. I also go with the staff member to present the case at the team, so the communication takes place.' (031, Social Worker, CAMHS)

'Having a caseload is important too because it makes you part of the team. As long as it's a small caseload. Rather than standing outside the team.' (031, Social Worker, CAMHS)

Some staff expressed a desire to have some form of transitions worker. Other staff who had not experienced first hand having the resources of a transition worker or other form of joint post, largely welcomed the idea of joint working as a positive move towards smoother transitions. Benefits cited were impartiality and local knowledge:

'We have tried to flag it up within CAMHS but I don't think it's an issue that is being addressed and it should be, but I don't think it is necessarily an issue that our colleagues in adult mental health are engaging with. We have tried to improve transition services, for example we tried to argue for the appointment of a transitions worker but we haven't met with any success, but that's not necessarily about transitions, that has happened in lots of areas where we have tried to improve services and put in bids that have not met with success.' (012, Psychologist, CAMHS)

'I think there's a lot to be said for having a worker that's specifically trained to target younger people and address these issues. We do know that when you have a special lead within an organisation, rather than a separate organisation, first of all they can act as an honest broker, or maybe if they get a nurse or an OT whatever, who takes the lead in adolescent areas, who has the local, as it were, patch knowledge. That's probably a good idea. We don't give enough resource or thought to that.'

But I must say it's a relatively small number and that person needn't have it as their substantive occupation.' (014, Psychiatrist, AMHS)

Others stressed the importance of joint working between CAMHS and adult services:

'One of the things I found particularly helpful and I think I've been in a slightly privileged position compared with the rest of the team is I do liaison with one of the community mental health teams and I meet with their duty worker, only once every three months, but it keeps both of us kind of in touch, we can put a face to the name and we can talk to each other about transitions that are coming up and also about some of the problems that we've had, so it just helps to have that face and that meeting...' (011, Nurse, CAMHS)

Others described CAMHS workers facilitating links between different parts of the service:

'...CAMHS workers going into the disability teams, learning disabilities and physical disabilities... Family Mental Health Liaison Service and that is just two people working into my CMHTs, so that's the transition post. And then there are the Adolescent Mental Health team working with our Early Intervention team – there are some transition issues there – and case working, and then also the Parental Mental Health team. That's interesting because it's not about the transition from CAMHS to Adults particularly, it's about the link between Adults, Mental Health and Children & Families teams, but it's CAMHS workers who are doing that linkage.' (022, Trust Manager)

In one Trust, monthly multidisciplinary transition forums facilitate movement between services. Managers in another trust were considering something similar:

'We're currently looking at something with our children's services at the minute, setting up meetings with different managers, sharing problems from each other's perspectives. Therefore, children who may be moving into adult services with mental health problems, would be a good element for that.' (033, Trust Manager)

Co-working by adult medical consultants and joint assessments with CAMHS colleagues was described by another participant, aimed at ensuring an element of relational continuity was present during transition:

'One of the adult consultants does a clinic here once a month, where CAMHS colleagues can look to go and see them, discuss the case, agree to do a joint assessment with them and where appropriate, take them up in adult services. And that's worked out very successfully.' (024, Trust Manager)

One participant said they would work jointly with a care coordinator in a referring team for about three months to make the transition easier and smoother for the client. This reinforces the often complex emotional and social processes involved in transition:

'One of the practices in our team is a lot of joint working with clients who are coming from different teams. I guess that would be quite a positive thing for a young person who's coming onto a new team, with different practices and sets of ideologies. So that would be quite a helpful thing, to get to know a new person while they are still under the care of the old team... I understand that it is difficult to completely switch over to a new team and set of professionals, so we share responsibility between care coordinators and gradually they get to see more of us and we start building up that relationship, so that transition becomes much easier rather than abrupt and sudden. We do that for about three months. This period is also used to prepare the person for transition, weaning away from their old team.' (034, Social Worker, CAMHS)

Others felt that, in addition to joint working, joint training would be helpful:

'More joint working or more understanding between CAMHS and AMHS. I'm thinking about how different things are, for instance in child protection. CAMHS focus is very much on protection of a child whereas AMHS is more about supporting the adult. We come at it from a different perspective. Maybe we need to be looking more at joint training and looking at the issues within the context of the family.' (026, Trust Manager)

'We don't have any shared training opportunities, any shared meetings which I think is unfortunate.' (012, Psychologist, CAMHS)

(iii) Staff having worked in adult services prior to CAMHS

Besides joint working, some participants described knowing someone who works in adult services acting as a facilitator for transition, or having worked in adult services prior to joining CAMHS was also beneficial for enabling transition in terms of knowledge and experience of adult teams' working practices, information requirements, expectations and use of appropriate documentation:

'Their new service manager is someone we know from adult mental health services which has actually made a big difference in terms of any problems. That is not about the protocol, that is much more about the personality...' (009, Nurse, AMHS)

'I was a psychiatric nurse with adults so I have an understanding because I've worked in that situation...' (007, Nurse, CAMHS)

'I think again because I've worked in adult for many years, it's been easier for me to get transfers going because I know what the adult teams need to hear, so it's about pushing the right buttons, so for me it's gone pretty smoothly because I know that they want to know about risks, that they want to know about the actual illness and medication, and they want the right bits of paperwork. I know that that's the kind of thing that's going to make a transition smoother. I know I was very welcomed in this team because of that knowledge, who helped everyone out to know how to do that and be heard. I just know what to say – if someone isn't listening to me, I'll know what to say to get them to listen, it's

cheating a bit really – although it's not really as this people need that service, but it means I can kind of get through some of the difficulties more easily.' (011, Nurse, CAMHS)

(iv) Inter-agency working practices

Staff described both challenges and positive experiences of inter-agency working for example, one challenge related to working with a variety of agencies involved in a particular case:, another related to challenges raised by issues of multiple boundaries and responsibilities as well as ownership:

'There is a similar sort of issue in terms of local authority involvement, I don't want to overplay this but it's just there's a multiple boundary there particularly the way you look at children who are in care.' (019, Trust Manager)

'An example I'm thinking of, it wasn't ever clear whose responsibility... this was someone under the Looked After Children team and about who was going to house somebody and who was going to pay for it...' (006, Nurse, AMHS)

Social care and housing were the most frequently cited agencies where both CAMHS and AMHS staff had experienced such difficulties. From the adult side, one participant felt integration of social care and mental health within adult services had not been well communicated to other agencies, particularly housing and was still causing confusion:

'I don't know how well communicated the integration was to other services and I'm convinced there are still teams who think social services and mental health aren't integrated. It crops up particularly with housing, who will say, "no this isn't for us, you need to talk to social services". What you are referring to doesn't exist any more!' (018, Social Worker, AMHS)

Positive examples of inter-agency working were most often cited between education and mental health:

'We are just at the moment forging links with Education so that young people again with first episode psychosis can be – they can be alerted to the fact that the young person is going to need additional input if they don't already have that and we just recently had a meeting with the Head of the Educational Psychology so again, that's been quite a difficulty because of the delay in getting young people back into some vocational training can really delay their progress.' (005, Psychiatrist, CAMHS)

'We have a link with (named college and individual), whose job is to support vulnerable people who are wanting to study and so people go along and meet with him and he can advise them on different courses they might like to do and give them support while they actually do the courses, so that's really helpful.' (015, Psychologist, AMHS)

A voluntary sector participant also described the positive benefit of CAMHS having had an educational psychologist seconded from the education service to work with parents and children in managing ADHD:

'Through Parent Partnership, they helped us, and CAMHS, they'd taken on the services of an Educational Psychologist who was seconded from the education service to work with parents and children, in managing the children's behaviour. They helped us to promote the group and we started from there.' (028, Voluntary Sector)

Participants generally felt working relationships with other agencies were easier if that agency was already involved in a young person's care:

'I think if they're already involved it's easier because you're already working together and there's possibly overlap in role anyway.' (026, Trust Manager)

(v) Service user preparation for transition

Most participants indicated a willingness to better prepare service users for transition, with some attempts being more successful than others:

'I think for some young people it must feel like quite an abrupt transition. It's not a process, it's an event which doesn't feel very comfortable.' (012, Psychologist, CAMHS)

'But it is a scary time. CPA meetings are there, but they can be quite intimidating for people, so talking them through the kinds of questions they might want to ask beforehand. It's difficult if the CMHT member coming is paying lip service, they don't expect to take on any responsibility or will have to go back to their manager, or they haven't thought who would be the young person's care co-ordinator. It's a bit random really.' (021, Nurse, AMHS)

For young people who are inpatients, transfer, particularly to Early Intervention services may happen on the ward:

'... all of the teams will meet at the board CPA so the client then meets the new people that are going to be looking after them. If they don't come through that then we go to the transfer CPA at CAMHS and meet them there and if we are co-working then we'll start meeting them in that last year with CAMHS.' (015, Psychologist, AMHS)

Participants cited examples of good practice whereby parents and carers visited inpatient facilities, reducing anxieties by involving people early on:

'I suppose the few cases I have been involved in, parents and carers have been quite heavily involved anyway and have been given the opportunity to come and look at services, that's one of the things that we've done when we have had a child that was likely to move up, particularly to inpatient services, we have allowed the parents to come in and look at the service, where they would be getting their services from. It is really standard stuff, it is about taking some of the fear out of adult services and getting people involved very early on and being flexible.' (013, Trust Manager, AMHS)

For most cases however, the onus is on CAMHS teams to initiate discussions with service users and families in advance of any changes in care provision:

'We try our best, even though it isn't an exact efficient transfer we do try our best, it comes back to us to pick up the pieces because we do know the child, they have been in our care for that period until they are transferred so we are in a sense, we take ownership for it because we are responsible, we feel responsible I should say even though on paper we aren't.' (008, Social Worker, CAMHS)

Participants agreed it was usually helpful for a CAMHS worker familiar to the young person to attend the initial meeting with adult service colleagues:

'I've also attempted to go with a young person to their initial involvement with adult services as a kind of handover to try to increase the likelihood of attending, rather than just send a letter to colleagues. So the young person can see the handover happening for them and where I have done that, it has been quite helpful in maintaining their engagement with adult services.' (030, Psychologist, CAMHS)

Some adult service workers felt a lack of knowledge and understanding of what adult services are able to provide, hindered CAMHS teams in realistically preparing service users:

'I would have expected the CAMHS team to have prepared them (service users) for it but sometimes I think they have an unrealistic expectation of what adult mental health services can provide and I that just goes back to they don't know what we do so how can they tell families...' (006, Nurse, AMHS)

...together with a general resistance by young people to change:

'I suppose there is resistance on the part of the young person not to want to move, they don't know the new worker, the set up, they have to re-familiarise themselves with somebody brand new, different styles of working, different techniques...' (008, Social Worker, CAMHS)

This may be particularly the case with young people who have had a psychotic breakdown:

'Young people who have had some form of psychotic breakdown and have engaged with the CAMHS team, often they don't want to move on. They know they're going to get something different. Part of that is just the fear of the Trust Manager and having to meet new people, but neither CAMHS or the adult service have really had long enough to be able to manage that. So probably the best thing we will often do is meet and have a joint meeting with the adult team and the family.' (027, Psychiatrist, CAMHS)

Young people and their families don't always feel they want ongoing services, particularly if they are going through a period, coincidental with the cut off age period for CAMHS services, when they are feeling relatively stable and well:

'When he stopped taking cannabis he became well reasonably quickly and sustained it and managed to get a job. So he and his mother didn't feel he needed to be referred to adult services because he was doing so

well but we were concerned about mum's lack of understanding about psychosis and how things can go wrong if he started smoking again. Because he needed inpatient treatment for quite some time when he was unwell. They were quite insistent but we persevered for several months. Anyway, we were on the point of closing it when he started to relapse. By this time he had gone beyond criteria for the early onset team, so we had to refer him to the local CMHT... He will probably be admitted and fall into adult services anyway, which is what we were trying to avoid. You can only do so much and be available as support, particularly for the mother. Which is a shame, but he will probably end up going into hospital because he didn't want the A initial referral to go through.' (031, Social Worker, CAMHS)

This reinforces challenges for longer-term decision-making and flexible case management if a young person is relatively stable and well at the time of transition. As highlighted earlier with regard to eligibility thresholds, adult services may not be willing to take on a young person when they are experiencing some stability and some other access mechanism or more informal follow up may be needed to prevent crisis returns to adult services.

4.3.4 Service cultures

This theme has three sub-themes: a perceived lack of confidence by adult service staff in working with young people; perceived individual versus family service cultures in CAMHS and AMHS and; impact of service culture differences on parents and carers.

(i) Adult services lack confidence with young people

Both CAMHS and adult services' professionals perceived anxiety and lack of confidence amongst adult service staff in managing young people:

'I think there is some difficulty in the way that some of our adult clients view adolescents and people don't always feel skilled in managing this client group...' (005, Psychiatrist, CAMHS)

'Sometimes, the high levels of anxieties in working with young people. They tend to think "children" and "I don't know anything about children".' (010, Psychiatrist, CAMHS)

This may partly be explained by the shift toward specialization reducing staff confidence in their skills and abilities. In contrast, some stated that staff already possessed the skills to work with young people, but acknowledged that a need existed for more generic training and practice aimed at tackling the underlying issues of anxiety reduction and restoration of confidence. Findings here had important implications for continuing professional development and training.:

'I've watched things become more and more specialist and had to spend more and more time dealing with relationships and the confidence, because people lose confidence. You have a generic social worker moves into mental health team and all of a sudden they don't know how to deal with children – how does that happen – and the opposite way, so it's

reducing some of the fear of talking to children – anybody can talk to children but it needs to be at different levels and for adult workers there's this whole issue of how you talk to children about mental illness, about their parent's mental illness.' (022, Trust Manager)

'I think most of the staff have got the skills but because they are not used that often, when they are called on to use them they have real concerns and it is something we all fear, is getting it wrong with children, I think these are the issues for adult staff, under-training. Again I think it could be relatively generic and that would make it much easier for staff to deal with that particular age group.' (013, Trust Manager, AMHS)

(ii) Individual versus family

Staff expressed the view that CAMHS and adult services have different cultural philosophies affecting transition. CAMHS was perceived as more family-oriented, inclusive and holistic than adult services, which were perceived as focused more exclusively on the individual service user:

'One is that CAMHS work in a much more systemic way than adult services. They often don't see the young person in the context of their family or community. Sometimes it feels like we're talking a different language... We would never see the young person in isolation. They are always with the system around them. I think adult services do find that more challenging and therefore their whole approach to intervention, resilience and recovery, whatever recovery means for that individual, is different to a CAMHS service. I think we're more positive. We look at how you can use the system to move the individual forward and looking for resilience in the individual.' (027, Psychiatrist, CAMHS)

'A big deal for the services is that Adults is not perceived as such a good service as CAMHS. CAMHS - well I suppose it's more person centred – it has a lower threshold, it involves the family more, it's a sort of kinder service than the rough and tumble of adult mental health services, so that is tricky for people and carers when I have spoken to them about the transition – it's a difficult one because you get less of a service and a different attitude towards people and that is problematic.' (022, Trust Manager)

CAMHS services were therefore seen as enabling a more proactive approach in engaging young people within their broader context of care. This raises issues about carers' expectations of communication and level of involvement with adult services, during and post-transition and how and by whom those expectations are managed. Voluntary services participants also reflected on the differing forms of intervention that tended to be offered and supported by CAMHS and AMHS:

'I think that's the big difference when they move over to adult services, is that those services are unlikely to be as proactive in working with that lack of motivation or ambivalence towards the services that are on offer. So I tend to find I get a letter written back to me from my adult colleagues saying they have offered an assessment appointment they've failed to attend and they are then going to close the case. And it's

unlikely that there will be much offered beyond that.' (030 Psychologist, CAMHS)

'CAMHS and adult services do seem to be very different. CAMHS seems much more gentle and supportive and very much focused on talking therapies, whereas adult services tend to be about dealing with absolute crises and dealing with medication as an intervention. I think if you're used to being in one and then you're having to move to the another that's a very big shock for people.' (032, Voluntary Sector)

However, some adult service staff say they do consider families and try to involve them, subject to the wishes of the young person. This participant also perceived that differences in professional background might impact on adult service counterparts' approaches to service users' families and carers:

'I always think that the family should be involved. Certainly, not if the client doesn't want you to have much to do with their family, then that's fine but I would always try to encourage the families to tell us what they know. I am a firm believer that you can't view any service user in isolation from their family and their environment. Sometimes we do dismiss families or not ask them and we lose a valuable resource there.' (006, Nurse, AMHS)

'I think sometimes that is harder for people who have a nursing background more than a social work background, they find it harder and tend to think this is my patient and it is confidential between us and therefore I shouldn't discuss anything with the family. Particularly if the person is living in the family home, I don't know how you can not include them, they spend a lot more time with the person than we'll ever spend with them.' (006, Nurse, AMHS)

Others said adult service philosophies, particularly in early intervention work, had changed or were changing to become more inclusive and CAMHS colleagues were not always aware of this. Ethical issues of confidentiality in relation to sharing of information were raised by one participant, and the impact of changing practice noted. However, guidelines on sharing confidential information were not referred to in ethical terms:

'...but the rules around confidentiality change quite drastically and we see them on their own. I don't think that happens so much now, I think a lot of people are very inclusive of relatives coming along and what have you but the culture is very different. It is a subtle difference because everything has changed so much and I don't think CAMHS are always aware of how much adult services have changed because we are a lot more inclusive, there is a lot about carers, like the Carers and Partners stuff so we are more inclusive of the parents or carers...' (009, Nurse, AMHS)

One perceived benefit of early intervention services as opposed to more general CMHTs was a continuation and extension of the inclusive, holistic approach young people, families and carers had become familiar with in CAMHS and found beneficial. While there are clearly resource elements impacting on the types and range of interventions offered, there is also an

implication that choice and availability of interventions is not only consistent with but embedded within each service's cultural orientation and philosophy. Logically, therefore, changes or adaptations to one have the potential to influence the other.

'I suppose we do – and I suppose this should be true with CMHTs also – we do automatically work with the families, which is helpful in engaging the clients and helping the transfers because then we get the parents' approval of us or at least the parents at least feel they know something about what we're doing and they can encourage. 80% or more than 80% of our clients still live at home or with a parent or guardian so they're very important, whereas with the CMHT, that's much lower, the family involvement isn't there.' (015, Psychologist, AMHS)

(iii) Impact of transition on parents and carers

There was also recognition, particularly by CAMHS staff, that the transition period from CAMHS to adult services time can be especially difficult not only for young people, but also for parents and carers. Participants often referred to the impact on parents and carers in terms of 'loss' or feeling 'cut out':

'We spend a lot of time liaising with schools, with other agencies and then moving on to adult it is very much about the individual so there can be quite big loss issues in relation to the parents or family structure or the supportive system who has been working with the young person.' (007, Nurse, CAMHS)

'That's right and our concern also is that we've always included the family as part of the intervention whereas our colleagues would not necessarily, automatically do that and at 18 a young person, in many cases, just be treated as an adult not really seen as part of the broader network and that causes a number of problems, particularly for parents who are carers and they feel that they've been completely cut out of the system.' (005, Psychiatrist, CAMHS)

This involves CAMHS staff particularly in preparing families for the withdrawal of CAMHS input and with it a form of support they are unlikely to receive once a young person has left CAMHS. The impact of transition on parents and carers therefore also needs to be carefully managed alongside the next stages of care for young people:

'I found that surprisingly, often it's not so much the young person that's bothered about the hand over, it's the family and again, I think I was taken by surprise by how much parents can value the kind of input and help that they've had, so it's actually been about involving parents in the idea that you're not going to be around for much longer and really talking about what that means and giving them the opportunity to think about the next steps...' (011, Nurse, CAMHS)

4.4 Discussion

A growing body of policy and research evidence has identified the need to prevent children becoming lost in the transition between child and adult mental health services which can result in loss of continuity of care, with negative effects on health, well being and potential (Forbes *et al*, 2002; While *et al*, 2004; Department of Health, 2006c; Kennedy *et al*, 2007). Continuity of care can be defined in many ways; in discussing the findings of this component of TRACK, the multi-axial definition of Freeman *et al* (2000; 2002) has been used as a framework for considering organisational structures, cultures, processes, resources and relationships which can constitute barriers and facilitators to transition and continuity of care. This framework has been used to organise the discussion because it best represents the data collected and interpretation of findings. A number of limitations should be borne in mind when interpreting the findings: these include the under-representation of participants from trusts in the West Midlands and of psychologists in the professional groupings. Humphrey, Ehrich and Kelly (2002) have emphasized the potential risks to service continuity posed by rapid organisational change which can distract attention and distort organisational priorities; thus, the potential for restructuring of organisations and services in the West Midlands trusts to have influenced professional participants' views and experiences cannot be disregarded in the interpretation of the findings discussed below.

4.4.1 Transition: informational continuity

Informational continuity has been defined as 'effective communication based on excellent information transfer following the service user' so that it is available whenever and wherever needed (Freeman *et al*, 2002; Department of Health, 2006c). Transition from CAMHS to AMHS requires the implementation of systems and processes for effective information transfer within and across organisations, and the provision of accurate and consistent information to children and families. Findings from this study identified both barriers and facilitators to informational continuity during transition. A key barrier to informational continuity was a general lack of two-way, inter-professional communication (written and spoken) across the CAMHS/AHMS boundary. Reasons for this were lack of co-location of administrators/gatekeepers (seen as crucial to information seeking) with the main service teams and widespread lack of a shared understanding about each other's services (public and voluntary sector) which made navigating the services and systems very difficult (see also section 4.4.3 *Transition: flexible and long-term continuity*). The use of inconsistent documentation, particularly with care planning approaches; different systems for electronic transfer of information and the transfer of CAMHS referrals to AHMS waiting lists which could result in lack of professional dialogue following referral, were also barriers to informational continuity during transition and not conducive to cross boundary working (see section 4.4.2 *Transition: cross boundary and team continuity*).

These findings are congruent with those of Richards and Vostanis (2004), who also identified variable communication and limited opportunities for joint discussion between services as problematic during transition from CAMHS to AMHS. Similar findings also emerged from the ECHO study (Burns *et al*, 2007) in relation to informational continuity in AMHS, where incompatibility of computer software systems between service teams (CMHTs) was a major barrier to informational continuity. At a national level, it has been recognised that delays in the IT programme have hindered crucial developments, including electronic recording systems, and that a phased process will address resource priorities (Department of Health, 2006c). In addressing such priorities, recognition should be given to supporting transition and informational continuity of care in CAMHS to AMHS. Recent policy guidance in *Transition: Moving on Well* (Department for Children Schools and Families and Department of Health, 2008) recommends that the development of transition care plans is co-ordinated by a key-worker and that information contained within them is shared with permission with relevant services and agencies; effective resources including administrative support are essential to achieve the successful implementation of this policy guidance.

In contrast, facilitators to informational continuity (see also 4.4.2; *et seq*) included joint working and liaison underpinned by effective communication and information transfer. Dedicated transition posts, monthly multidisciplinary transition forums, co-working between care co-ordinators, psychiatrists and the importance of early communication to foster smooth transition, coping and adjustment by young people and their families were all seen as beneficial. Such joint working and liaison is likely to facilitate several aspects of continuity, over and above information continuity (Maitra and Jolley, 2000; Department for Children Schools and Families and Department of Health, 2008). Training in communication skills and leadership for health and social care professionals have also been recommended to enhance informational continuity in child to adult services (Royal College of Nursing, 2004; McDonagh and Viner, 2006). Overall, these findings suggest that training could be beneficial in overcoming some of the barriers identified, as could disseminating exemplars of 'best practice' in facilitating informational continuity.

4.4.2 Transition: cross boundary and team continuity

Cross boundary and team continuity requires effective co-ordination of services by teams and external agencies (Freeman *et al*, 2002). This is underpinned by informational continuity (see above). Factors which can impact on cross boundary continuity during transition are team/service cultures, structures, processes and professional roles. Findings from Track Stage 3 confirm that a 'cultural' divide between CAMHS and AMHS impacts on transition and working across organisational boundaries. CAMHS was perceived as person-centred, holistic, family-oriented, gentle, supportive and focused on talking therapies. In contrast, AMHS was described as dealing with crises, medication-oriented and less likely to view young people in a family context. Negotiating these boundaries during transition was

thought to be a 'cultural shock' for young people and carers. However, AMHS were reported to be moving to greater inclusivity of families and carers. Early Intervention services in particular were noted as continuing the more holistic, family-focused philosophy of care which operated in CAMHS. These findings are consistent with other studies which have reported a similar cultural divide not only between CAMHS and AMHS but child/adult services in other specialities, which poses a challenge for service delivery and adjustment/coping of young people and families (Kipps *et al*, 2002; Singh *et al*, 2005).

Developing services which effectively bridge the cultural divide and enhance cross boundary continuity requires, in part, a focus on continuing professional education to ensure that all involved can place the needs of the young person at the centre of the transition process (McDonagh and Viner, 2006; Department for Children Schools and Families and Department of Health, 2008). A key finding of this study was that both CAMHS and AHMS staff perceived the latter to lack confidence and skills in managing young people, which led to considerable anxiety. Shifts towards professional specialisation were thought to account for this; solutions proposed were to offer more generic training, also endorsed by McDonagh and Viner (2006) who suggest a common multidisciplinary training programme in adolescent health and transitional care for adult and child teams.

Another key finding of this stage was that professionals lacked clarity, information and understanding about each other's service structures, availability and also those of voluntary organisations, which impeded transition and cross boundary working. The benefits of transition worker roles were viewed as helpful to both cross boundary and relational continuity, as were joint appointments between CAMHS and AHMS, co-working by psychiatrists, care co-ordinators and multidisciplinary transition forums (see section 4.4.4 *Transition: relational, personal and therapeutic continuity*).

Other barriers to cross boundary and flexible continuity were created by different thresholds and eligibility criteria for service access which operated between CAMHS and AHMS (see section 4.4.3 *Transition: flexible and long-term continuity*). Challenges for interagency working were lack of clarity over accountability for providing and paying for services, together with a lack of communication and confusion about the integrated nature of health and social care in AHMS. Offsetting these experiences were positive exemplars of interagency working, notably between CAMHS, education and the voluntary sector where secondment of an educational psychologist to CAMHS had proved beneficial in managing ADHD.

Resolving many of the barriers to cross boundary continuity during transition could be helped by the development of transitional care plans, transition protocols and guidelines (see also section 4.4.1 *Transition and informational continuity*). Participants in this study did not make reference to the existence of transition pathways (as part of integrated care pathways) and the only reference to a transition protocol was that it was out of date. These findings resonate with those of Stage 1 in relation to the

variable content of protocols their complex patterns of use and utility in practice which suggests a policy –practice gap exists (see also Section 6.3.1). These findings are similar to those of Treasure *et al* (2005) who also found a lack of local protocols and procedures to guide CAMHS to AMHS transition. Recent policy guidance identifies a need for multi-agency transition protocols to be in place to inform transition (Department for Children Schools and Families and Department of Health, 2008). Stage 1 mapping found that transition protocols were in place in many mental health trusts; Stage 3 shows suggests that clinicians are either not aware of these protocols or do not consider them useful in practice.

4.4.3 Transition: flexible and long-term continuity

Flexible continuity encapsulates the need for services to adjust to the needs of individuals over time (Freeman *et al*, 2002). This form of continuity is dependent on flexible care planning and monitoring underpinned by effective communication and requires a range of services and resources to be available throughout the process of transition. In contrast, long-term continuity was defined by Freeman *et al* (2002) as the provision of uninterrupted care for as long as the service user needs it, recognising that the potential for gaps to occur during transitions can result in a negative impact on continuity.

Key findings from Stage 3 are that differing thresholds and eligibility criteria between CAMHS and AMHS form barriers to flexible, long-term and cross boundary continuity during the process of transition. In general, CAMHS were perceived as working with different client groups, becoming involved at lower thresholds encompassing low mood, relationship difficulties and self-harming. In contrast, AMHS were seen as operating higher thresholds relating to serious mental illness (e.g. psychosis), forensic histories and clients requiring inpatient admissions. Concerns were also expressed that it was difficult to transfer young people to AMHS when they were in a stable state following treatment, i.e. not in a crisis state. Overall, the perception was that AMHS were not meeting the needs of young people beyond those with chronic, serious and enduring conditions. Others with self-harming problems, depression, and emerging personality disorders could not be transferred and this resulted in them being retained by CAMHS until early adulthood, or returned to the care of their GP. Similar problems were encountered through the operation of rigid age criteria (18 years) by AMHS before transition could be initiated, even in cases approaching 17 years of age. These findings resonate with those of Vostanis (2005) in the UK and Cosgrave *et al* (2008) in Australia about young people with significant mental health need who can fall in the gap between CAMHS and AMHS. Other prominent problems were lack of adolescent-specific resources, in particular inpatient facilities and out-of-hours services.

We confirmed that AMHS lack provision for young people with substance misuse, attention deficit hyperactivity disorder (ADHD), autism and learning disability (Lamb *et al*, 2008) with parents and carers having to depend upon voluntary organisations for information and support. Loss of funding support from social care for the voluntary sector has had an adverse impact in one

area. A number of solutions were proposed by participants, including lowering eligibility thresholds, developing up to date transition protocols incorporating targets, increasing the knowledge and skills in AMHS to facilitate working with ADHD and other conditions, and the creation of link worker posts and outreach workers interfacing with schools to assist management of autism and ADHD.

Overcoming these barriers and implementing the standards enshrined in National Service Frameworks (Department of Health and Department for Education and Skills, 2004) for age appropriate services and for transition services for children with complex needs (Department for Children Schools and Families and Department of Health, 2008) is essential to avoid inequity in a health service committed to choice and the removal of health inequalities. Current policy guidance specifically identifies palliative care, mental health and learning disability transition services for children but does not refer to ADHD and autism. Our findings suggest that this is a major omission and young people with neurodevelopmental disorders are at very high risk of poor care across transition boundaries.

4.4.4 Transition: relational, personal and therapeutic continuity

Freeman *et al* (2002) defined this form of continuity as the 'need to provide one or more individual professionals with whom the service user can maintain a consistent professional relationship'. Factors impacting on this during transition include availability of key professionals, their roles and responsibilities, professional workloads, case loads and workforce stability. For the young person and parent, the years spent with CAMHS will have involved the development of trusting therapeutic relationships which can make the transition to adult care seem daunting, particularly where frequent and helpful interventions have occurred (Department for Children Schools and Families and Department of Health, 2008). Establishing positive therapeutic relationships with new professionals is vital therefore to ensure service users' and their families' engagement with AMHS.

In this study, professionals identified several concerns that service users and carers have about transition to AMHS. These included fear of the unknown, reluctance to move from CAMHS and a feelings of 'loss', uncertainty about what AMHS offered and feeling intimidated at the first CPA meeting. Concerns were specifically expressed about abrupt transition (not a process but an event). Preparation for transition was considered helpful, with professionals indicating willingness to be involved; exemplars of helpful interventions were early co-working and meetings between CAMHS/AMHS, children and families. The importance of establishing early joint working in preparing children and families for transition well in advance (by ages 13-14 years), with adequate time to establish good relationships has been emphasized in many reports (Royal College of Nursing, 2004; Department for Children Schools and Families and Department of Health, 2008); the point has also been made that 'when

children enter a paediatric service, they should know when they can expect to leave it' (McDonagh and Viner, 2006, p436).

The benefits of transition key-workers and joint appointments between CAMHS and AMHS were recognised in terms of ensuring relational and therapeutic aspects of continuity, where the transition worker stayed with the service user and continued to work with the new care co-ordinator in AMHS for some time. Other arrangements which helped relational continuity were co-working between psychiatrists and care co-ordinators and joint assessment with CAMHS colleagues over the transition period. The importance and value of key transition workers in establishing close working relationships and contact with young people and families; offering support, information and advice; acting as an advocate and co-ordinating effective service delivery has been emphasised (Department for Children Schools and Families and Department of Health, 2008). However, lack of funding resources for such posts was reported by some participants in this study.

High workloads, staffing shortages, use of agency and locum staff and high staff turnover can disrupt relational, therapeutic and longitudinal continuity in adult mental health services (Burns *et al*, 2007). Similar findings were found in this study, where high CAMHS and AMHS team workloads and lack of adequate staffing resulted in lengthy waiting lists and professional staff struggling to cope; these were perceived as major barriers to transition. Knock-on effects of staff shortages were more rigid interpretations of eligibility criteria (see 4.4.3 above).

4.4.5 Conclusions

Transition has been recognised as a multidimensional, multidisciplinary, lengthy process continuing on into adult care, marked by joint responsibilities in multidisciplinary working (Royal College of Paediatrics and Child Health, 2003; Royal College of Nursing, 2004; McDonagh and Viner, 2006). Findings of this study suggest continuing problems with multidisciplinary working in some areas relating to transition and continuity of care. A number of barriers and facilitators for transition and continuity of care were identified, which are summarized in Tables 20 and 21 below.

Table 20. Facilitators to transition and continuity of care

Facilitators for CAMHS/AMHS transition	Positive impact on dimensions of continuity of care
Dedicated key-worker transition posts Joint appointments across CAMHS/AMHS Secondments CAMHS/Education	Relational, personal and therapeutic continuity; informational and cross boundary continuity
Multidisciplinary Transition Forums Co-working between psychiatrists, care co-ordinators	Informational, cross boundary, team continuity
Early communication in preparation for transition	Personal, relational and therapeutic continuity; informational continuity
Shifts to greater inclusivity for parents/carers in AMHS	Personal, relational continuity
Management awareness of the need to provide services for a wider range of provision in ADHD, learning disability	Flexible and long-term continuity

Table 21. A summary of barriers to transition and continuity of care

Barriers for CAMHS/AMHS transition	Negative impact on dimensions of continuity of care
Lack of two-way communication between CAMHS/AMHS	Informational, cross boundary and team continuity
Inconsistent use of documentation, CPA approaches, different systems for information transfer	Informational, cross boundary and team continuity
Different cultural philosophies in CAMHS and AMHS	Cross boundary, team and personal and therapeutic continuity
Lack of confidence of AMHS in managing young people	Cross boundary, team, relational, personal and therapeutic continuity
Lack of clarity, information and understanding between CAMHS and AMHS professionals on service structures	Cross boundary, team, informational continuity
Different thresholds and eligibility criteria for service access	Cross boundary, team, flexible and long-term continuity
Few posts/limited funding for transition key-worker roles	Cross boundary, team, informational, personal, relational and therapeutic continuity
Limited AMHS services for ADHD, autism and learning disability	Flexible and long-term continuity
Lack of inpatient facilities, out-of-	Flexible and long-term continuity

hours services for CAMHS service users	
High workloads, case loads, staffing shortages, lengthy waiting lists for AMHS	Relational, personal and therapeutic continuity, cross boundary and team continuity

5 Stage 4: Case studies

'...I have no knowledge of what's happening. I'm in the dark.' – Parent of service user

'Well, basically they said you, I, being in adult services you don't get as much time, there's, they don't spend as much time with you and well basically you're an adult and it would be much different and you've gotta like be a bit more responsible for yourself and that sort of thing, yeah, but if you do need them they are there but the time, the time isn't as lengthy.' – Service user

'...even though he is an adult, it's still your child and I would still like to know what is going on' – Parent of service user

5.1 Aims

The aim of Stage 4 was to describe the transition experiences of service users, carers and mental health professionals and to investigate the factors that promote and hinder successful transition.

5.2 Method

We conducted a series of case studies of transition using semi-structured qualitative interviews with a sample of service users who had completed transition, and (where possible) their parents/carers and responsible clinicians involved in transition from both CAMHS and AMHS.

5.2.1 Sampling method

A purposive sampling design was used to select subjects for interview from the Stage 2 case note tracking study population. The aim was to interview young people who had undergone the transition (defined as actual referrals) but who experienced different process and outcome. A purposive sample of twenty service users was initially identified comprising:

- 10 service users who remained engaged with AMHS 3 months post-transition, and,
- 10 service users who were not engaged with AMHS 3 months post-transition.

Within each of the above groups we sought to identify and sample cases where there was, and was not, evidence of joint working between agencies around transition. Within this primary sampling frame we also sought to achieve range and diversity in terms of location (trust site), diagnosis, gender, ethnicity and whether or not the service user was an age outlier¹ at time of transition (see Table 22).

5.2.2 Recruitment of the sample

In all cases, attempts were made to contact the service user's AMHS key-worker in order to assess the appropriateness of approaching the service user for participation in the study. In cases where the service user had not engaged with AMHS, or where AMHS key-worker felt unable to comment, attempts were made to contact the service user's CAMHS key-worker.

¹ Patient is an age outlier if at the time of their transfer of care to adult services, he or she was more than one year older, or one year younger than the transition boundary age (e.g. in London sites, boundary is 18 so age outlier if aged 17 and under or 19 and over; in West Midlands sites, boundary is 17 so age outlier if aged 16 and under or 18 and over).

Failing this, attempts were made to contact the service user's GP to establish whether there was any clinical reason why the service user should not be approached by the research team. No young people were contacted without the knowledge and consent of the AMHS team, CAMHS team, or GP.

After clinician consent was obtained, a member of the research team wrote a letter or telephoned the user (following clinician advice) to provide information about the study and invite them to participate. Young people and their parents who participated in interviews received £20 for their time and travel expenses.

If a service user either declined to be interviewed or was deemed clinically inappropriate for participation by the clinician contacted, reselection to replace that case was done where possible with a case matched in terms of the primary sampling variables. When each service user interview was completed we then sought the service user's consent to interview their carer, and the CAMHS and AMHS clinicians involved in their transition.

Parents and AMHS and CAMHS clinicians were only invited to participate in interviews if the service user had given written consent for the researcher to contact them. In some instances, permission was not given for the parent and/or the clinicians to be contacted. In other instances, the clinicians were not available or time limitations prevented further interviews taking place.

5.2.3 Interview method

Semi-structured interview schedules were developed for service users, carers and CAMHS and AMHS clinicians (see Appendices 5 - 8) based on pilot interviews with CAMHS and AMHS clinicians at St. George's, University of London, prior to data collection. Interviews with service users and carers were conducted face-to-face at either the CAMHS or AMHS service or the service user's/parent's home. All clinicians opted to be interviewed at their services.

Service users, carers, and clinicians were interviewed separately except in one instance, where a service user requested that his parent be present during his interview (the parent was later also interviewed separately). Probe questions were structured to cover key themes, but the interview was also responsive to issues emerging from respondents' accounts. All interviews were audio-recorded and transcribed, then downloaded onto NVivo software for coding and analysis.

5.2.4 Data management and analysis

The primary objective of analysis was to describe the process of transition and to obtain accounts of the process from the perspectives of all key parties involved in greater detail than would otherwise be possible using data from the case note audit (Stage 2). The key focus of the interviews was upon preparation for transition, transition experiences, transition outcomes and factors identifiable as related to positive or negative transition outcomes. Within this broad, predefined thematic structure a

coding frame was developed collaboratively by the study team and the coding of all transcripts was done by K Hovish.

A reflexive approach was taken, continuously reviewing and refining the topic guide and coding framework to ensure that all areas that the respondent had spoken about had been covered. Data were summarised in relation to these emergent themes with emphasis upon description of the range of experience reported. While NVivo was used to code, share and store data for retrieval the final case study analysis involved compilation of case dossiers, comprising multi-perspective accounts of each case (i.e., manually drawing upon and triangulating data from service users, carers, and CAMHS and AMHS clinicians). These dossiers were analysed thematically to identify factors that might promote or inhibit effective transition.

Summaries of case dossiers are available from the PI on request.

Table 22. Characteristics of stage 4 participants and extent of available multi-perspective data in achieved sample of cases.

Case	Primary sampling variables		Secondary sampling variables					Interviews completed (in addition to service user)		
	Engaged at 3 mths with AMHS	Evidence of Joint Working	Site	Age Outlier	Gender	Diagnosis category	Ethnicity	Parent	CAMHS clinician	AMHS clinician
A	Yes	Yes	L2	No	Male	Serious & Enduring	White	YES	No response	Clinician left service
B ⁽¹⁾	Yes	Yes	L2	No	Male	Emotional / neurotic	Asian	YES	Service closed down	Clinician not available
C	Yes	Yes	L3	No	Female	Emotional / neurotic and Eating disorder	White	YES	Clinician left service	YES
D ⁽¹⁾	Yes	Yes	L3	No	Female	Serious & Enduring	Black	No service user consent to interview parent or CAMHS clinician		YES ⁽²⁾
E	Yes	Yes	L3	No	Female	Serious & Enduring	Black	Unable to contact	Unable to contact	YES ⁽³⁾
F	Yes	Yes	WM2	No	Female	Emotional / neurotic	White	YES	YES	YES
G ⁽¹⁾	Yes	Yes	L3	Yes (+)	Male	Serious & Enduring	Black	No service user consent to interview parent.	Unable to contact	YES

H	No	Yes	C&W3	Yes (-)	Female	Emotional / neurotic	White	No service user consent to interview parent.	YES	clinician left service
I	No	Yes	L2	No	Male	Emotional / neurotic	Black	YES	YES	YES
J	Yes	No	L2	No	Male	Serious & Enduring	Black	No service user consent to interview parent or clinicians		
K	No	No	WM3	No	Male	Neuro-developmental & Emotional/Neurotic	White	YES	Clinician left service	YES

(1) Service users B, D and G represent 3 of the 4 'optimal transition cases' identified in Stage 2 (i.e. they had at least one transition planning meeting, a period of parallel care, good information transfer, and engagement or appropriate discharge at 3 months post transition)

(2) Key-worker interviewed no longer involved in the service user's care. Service user transferred to another service.

(3) Current key-worker interviewed. The key-worker involved at transition having left the service.

5.3 Results

5.3.1 Characteristics of the sample

For reasons discussed later (see section 5.4.1 *Issues and limitations*) achieving the intended sample proved difficult. An achieved sample totalling 11 service users was interviewed. Although each combination of the two primary sampling variables are represented within the achieved sample by at least one case, cases in which service users failed to engage or where there was no evidence of joint working are under-represented. By the end of the recruitment period (early July 2008), a total of 27 interviews were completed. These comprised the 11 service user interviews together with six parents, three CAMHS clinicians and six AMHS clinicians. Table 22 describes the characteristics of the sample and the extent to which data from carers and clinicians is available in each case.

The analysis of these interviews revealed a variety of themes which we set out below. These are grouped in terms of the experience of CAMHS, preparation for transition, accounts of transition, the outcomes of transition and factors impacting on transition process and outcome.

Specific service-related characteristics to bear in mind include that three of the Stage 4 participants (service users A, B and J) were transferred from adolescent units. Of the total eleven, seven were referred to CMHTs (service users B, C, D, F, I, J, K), one to an adult psychotherapy unit (service user H), one originally referred to a CMHT but then transferred to an Early Intervention in Psychosis Team (service user G), one to an adult inpatient unit but then transferred to an Early Intervention in Psychosis Team (service user E) and one to an Early Intervention in Psychosis Team but then transferred to a CMHT (service user A).

Throughout this chapter we have provided 'vignettes' to give examples of service users' experiences of mental health services and transition. These are written from the perspective of the service users, which sometimes differed from their carers' and clinicians' views. The examples selected were of the most forthcoming service users interviewed.

5.3.2 Preparation for transition

During the interviews, participants were asked to describe the three key mechanisms for promoting continuity of care at transition that they may have experienced; these were transfer planning meetings between CAMHS and AMHS, periods of parallel care involving both CAMHS and AMHS and information transfer using more conventional referral mechanisms.

Planning meetings

A majority of the young people interviewed (Cases A, B, C, D, G and I) reported attending at least one transition planning meeting which were attended by key-workers - usually from both CAMHS and AMHS - and at

least one parent in most cases. These meetings were usually a few weeks preceding the transfer. One AMHS key-worker described such a meeting:

'... I met [the service user] and got to hear a little bit about what work was being done at CAMHS, what sort of outstanding work needed to be done when she was transferred to adult mental health services and we took her from there really.' (AMHS key-worker to service user D)

Transition planning meetings helped allay parents' fears about transfer. For instance, service user A's mother said she felt *'a bit taken aback'* when her son's CAMHS key-worker told her about the move because she felt that her son was not yet an adult or ready for it but admitted she felt better once she had attended the meeting.

Service user C noted that although CAMHS and AMHS professionals were involved at her transition planning meeting, she had never met the CAMHS worker before and found this somewhat distressing (her former CAMHS key-worker did not attend the meeting because she had left the service shortly before the transfer):

'... I just thought it was another meeting...I just didn't see the point of that lady from CAMHS being there, she didn't know me, she didn't know anything about me, all she knew was what was on my file, she'd never met me and yeah, [AMHS key-worker] is really nice, the psychiatrist didn't really say much, I didn't really see any point in their being there really.'

Both the CAMHS and AMHS clinicians interviewed for service user I noted the difficulties they had in finding a time when they were both available as well as in engaging the service user in the meeting; he did not attend the scheduled appointments and when he did eventually show up to a meeting, he was very late.

In the case of service user E, it was difficult to establish whether there were any transition planning meetings due to neither key-worker involved being available for interviews and the service user being an inpatient at the time of transition.

Service users F, K, H and J all stated that they did not have any transition planning meetings. The CAMHS key-worker for service user F felt in hindsight that it would have been beneficial to have a meeting involving the AMHS key-worker, service user and her family but noted that *'...getting the time to do that and the professionals together to do that is often, is often difficult.'* However, the AMHS key-worker for F felt a transition planning meeting was not necessary as it was not a complex or chaotic case. In the case of service user K, the AMHS clinician commented that while such a meeting might have been useful, the service user may have found it intimidating. Service user K's mother, however, felt that a meeting would have been useful to get K introduced to new staff, particularly because of him having autism spectrum disorder. The key-worker for H commented that transition planning meetings could sometimes be helpful but did not feel it was necessary in this case.

K cannot remember his referral to CAMHS. He explained that his mother took him out of school when he was 15 as he was having problems there and did not want to go to school. Shortly after this she took him to see a psychologist. K saw several professionals linked to the school, Social Services and CAMHS, all around the same time, and has trouble remembering who is related to which service.

K was diagnosed with Obsessive Compulsive Disorder, social anxiety, generalised anxiety and eventually Asperger Syndrome. He is angry that being diagnosed with an Autism Spectrum Disorder took several years, 'after seeing loads of people'. He has a low opinion of CAMHS, particularly as he saw many different people there, including trainees, and commented that this made him feel that he was just there for them to learn. He did, however, find seeing the psychologist at CAMHS helpful.

K said that the only positive thing from CAMHS was his diagnosis of an Autism Spectrum Disorder because this led to referrals to other services that have been able to help him. He describes feeling angry and disappointed that this diagnosis came so late as he feels that he has 'wasted' growing up and if it had been identified earlier he would have been 'on the right track a lot sooner'.

In his recollection of the transition to adult services, K said his key-worker told him during his last couple of appointments that he would no longer be receiving any help from CAMHS. He thinks she went on to say there was no point in him going to AMHS as he would not need their services and they would not be able to help him.

Since being referred to AMHS, K said he has attended two or three appointments and has been waiting 12 months to receive Cognitive Behavioural Therapy from a psychologist. AMHS has not met his expectations as he was hoping he would receive 'more constructive and positive' help than he received while with CAMHS. He is currently involved with an autism support service, found via self-referral. He finds this extra support helpful and says people take him out to work on social skills and confidence. He feels that the help received thus far from both child and adolescent and adult mental health services has been 'very bad.'

Parallel care

In cases where it was possible to establish whether there was a period of parallel care or joint working between CAMHS and AMHS, the experiences of the young people varied widely. In the case of D, the key-worker said there was a three-month period of joint working between CAMHS and AMHS. The same key-worker said she attempted to have a two-month period of parallel care for service user C while CAMHS were still in charge of care where she could get to know her but, with hindsight, felt that a four-month period may

have been better due to the number of missed appointments by the service user during this time. This key-worker noted that the local CAMHS was good at acknowledging the difficulties of transition and tried to have joint working with every case that was transferred despite potential difficulties:

'...I like the idea of joint working for a couple of months because I think it's definitely in the best interest of the client and it's helpful for the worker who's taking on the case but I do think there's this issue of, you know, if someone's on your caseload and something goes wrong you're responsible for it.....in discussions that have come up with other CAMHS cases and I've said it would be really useful to, to co-work the case for a couple of months people have been really, really unwilling to do that for that reason and usually they will say but if something goes wrong with that client whose responsibility is it? And for CAMHS I imagine they're quite keen to just get people transferred, they're no longer responsible for the care, the new team is, the new team's thinking I don't want to kind of get involved because what if I get all this work before it's actually my case? Which is awful and isn't, isn't at all in the best interest of the client but I think it does happen, definitely. Yeah, so that's probably one of the biggest issues I think.'

The key-worker commented that D was involved with three services simultaneously – CAMHS, AMHS and supported accommodation into which she had just moved:

'...she'd just moved into a supported accommodation facility for young people who had experienced psychosis so she had her work with CAMHS happening, she had work with me started with adult services plus she was living in this new environment who had twenty-four hour key-workers there so she kind of had three services all working with her quite intensively for two or three months...'

In striking contrast, in case G, the AMHS key-worker noted that his team decided not to have a period of joint working due to the service user experiencing an additional transition (an assessment phase for accommodation before moving to permanent supported accommodation). The team therefore decided to step back while G was getting used to new accommodation and the members of staff there.

In case I, CAMHS and AMHS key-workers differed in their perceptions of the limited parallel care that had been undertaken. The CAMHS key-worker said there was no period of parallel care and it but that this would have been helpful, while the AMHS key-worker said that the service user had seen CAMHS a couple of times after the transfer to adult services but that a longer period of parallel care would have been better.

In cases H and K it was noted that there was no parallel care between CAMHS and AMHS, although the key-worker felt that a couple of sessions of joint working would have been beneficial. While not saying parallel care would have been beneficial, the key-worker to service user K acknowledged that it would have been helpful to have done the transfer earlier while

CAMHS were still seeing him, or for CAMHS to have continued to see him past age of transfer.

Information transfer at referral

In all cases where clinician interviews were completed, it was reported that transfer involved a written referral letter from either the consultant psychiatrist or the key-worker working in the CAMHS. In cases D, C, G and I letters were sent to the AMHS team, although the AMHS key-worker for service user I noted that he would have been transferred to the adult service anyway due to his age at the time of his inpatient admission. His CAMHS key-worker noted that she also made several phone calls to AMHS for transition. In two cases (K and H) CAMHS key-workers sent a referral letter through a single point of entry system, and the referral was then passed on to the relevant adult team. The key-worker for H described the referral letter as outlining the nature of contact with CAMHS, ongoing difficulties, and what the key-worker wanted the service user to receive at AMHS.

5.3.3 Accounts of transition

In addition to parallel care and transition planning meetings, users were sometimes prepared in more informal and low-key ways for their transition to AMHS. Service user G said that his CAMHS key-worker had informed him about the move to AMHS and he met with the AMHS key-worker a couple of times before transfer. G said that he was not pressured into moving and that it was just done *'gradually just slowly, slowly I moved up to the adult services when I was ready...I think it was a good transition, I don't really know what could be any different. I didn't notice it too much. I thought it was good'*.

Similarly, service user A and his mother said that being informed about transition to AMHS a month before it happened was helpful, thought the transition was smooth, and were not able to think of anything that could be improved. The mother commented that it would have been helpful to have received more information about the AMHS team (an Early Intervention service). The parent of B also felt that preparation for transition was adequate and that the transition went well, but noted that B did not want the transition to occur.

Service user I was informed by his CAMHS key-worker in person and by letter of the move to AMHS. The CAMHS key-worker commented that she was concerned regarding the termination of their therapeutic relationship, particularly as he had difficulties in building relationships. Of note was the fact that I needed admission to an inpatient mental health unit due to suicidal ideation at the time of transition, and this was his only admission.

Service user D reported that she was told when she began attending CAMHS that she would be transferred at age 18 to AMHS: *'I was told about the transfer and I would be meeting the new care co-ordinator and the transfer would happen slowly...they explained how different it would be...'*. C was also told at her first CAMHS appointment that she would be transferred to

AMHS within a few months as she was close to her eighteenth birthday. She felt therefore that the referral to CAMHS was *'pointless'* and *'a waste of time'* and hence did not *'open up'* much because of this. Her key-worker noted that she missed a lot of appointments with CAMHS and therefore the transition was not as smooth as it could have been. Case H had a similar experience when her CAMHS key-worker told her that she was reaching the transition boundary, *'which I didn't think was...that great because I hadn't been seeing her for that long...she couldn't really do much with me because I'm going to be seventeen soon'*. She did not think there was anything that helped her prepare for the move to AMHS although she did meet her AMHS key-worker before transition for an assessment. Case E remembers someone approaching her about the transition to AMHS while she was an inpatient, but was not able to say much else about it.

Some users and carers were quite disappointed with their preparation, or lack of, for the transition. F said that she was told at her last CAMHS appointment that she was going to be moved to adult services and felt unprepared, while her mother said they did not get any information about it. However, her CAMHS key-worker said she spoke to F about the transfer *'a couple of times before her last appointment'*. K and his parent also said that they were told about the move to adult services at the last CAMHS appointment. J said that although he was told in person and then written to about two weeks later with details of AMHS service, he felt that the transition *'was just all of a sudden...I didn't really like it.'*

Parental involvement

Parental involvement with CAMHS and AMHS varied from case to case. In cases where users did not engage with AMHS, parents had no involvement. In case F, the involvement of her parent changed very little before and after transition as her mother continued to accompany her to AMHS appointments as she had done with CAMHS appointments. However, the CAMHS key-worker noted that the good rapport both the service user and her mother had built up with the CAMHS consultant may have led to some anxieties regarding the transfer to adult services.

In one unusual case (C), the AMHS key-worker noted that C's mother had not been involved with CAMHS at all but had increased involvement with AMHS and had developed a good relationship with the AMHS key-worker. C's mother confirmed this and felt that she had become much more involved in her daughter's care following transfer to AMHS. This change seemed in most part to be due to the attempts of the AMHS key-worker to involve the family when C was first transferred to her. C, however, felt that her mother's involvement had not changed from CAMHS to AMHS.

More commonly, parents tended to be less or not involved with AMHS than with CAMHS and sometimes not involved at all. Service users A, D and G all said that they preferred not having their parents involved in their care any more. G said, *'the adult services they don't tell your parents or anything, everything's confidential and it's between you and the person so it's much better, it's like a lot less stress.'* His AMHS key-worker noted that while the team generally did have a close involvement with families, in this case the

team had respected G's wishes: *'I think it would have maybe caused more friction...at the time, especially because all his kind of ideas were based around his family'*. However, he went on to say, *'...in hindsight it would have probably have been better to be more involved with the family early on'*. In case H, the parents were not involved in either CAMHS or AMHS as, according to her key-worker, she made it clear she did not want her family involved when she first went to CAMHS.

In contrast to the other young people interviewed, J said that although his mother wasn't as involved as she was when he was at CAMHS, he would like her to be more involved because *'it's difficult sometimes if you're isolated, cause I'd rather have people to support me.'* Two of the parents interviewed also said that they wanted to be more involved with adult services. In case B, his mother was involved with CAMHS, felt that they knew what was going on, and attended CAMHS meetings. With AMHS she felt that she was not kept informed and wanted someone from AMHS to be in contact with her so she could get in touch with them when she had concerns. Similarly, A's mother said that she would accompany her son to all CAMHS meetings. She was also involved with the Early Intervention team that A went to prior to transferring to AMHS and received written reports from them. However, now she felt that she was not involved with the CMHT, had never met or spoken to her son's key-worker, and felt *'left in the dark'*.

In case E, parents were not involved except for the occasional CPA meetings. E explained that *'they don't believe in what these people [the EI team] are doing'*. Her AMHS key-worker had tried to involve the family in family work but they had not engaged. The key-worker also said the family had *'certain religious ideas about her illness'* and that E often changed her mind about whether she wanted her family involved or not.

Relationships with key-workers

Young people's relationship with key-workers ranged from positive to neutral. Service user A said that he had a good relationship with both his key-workers, and his mother commented that his CAMHS key-worker was good male influence in his life. A did not mind the change in key-workers due to the transition. D also got on well and engaged with both her CAMHS and AMHS key-workers. G seemed neutral towards both key-workers but was well-engaged with both. F also had a good relationship with her CAMHS key-worker according to her parent and the AMHS key-worker. C reported good relationships with both CAMHS and AMHS key-workers but the CAMHS key-worker had left her post shortly before transition and had not been involved in the process. Two cases (I and J) described their relationships with their CAMHS key-workers as good, but one did not engage with AMHS (I) and the other attended AMHS just with regard to his medication (J).

Several young people experienced changes in their key-workers additional to the one resulting from the transition from CAMHS to AMHS. In case K, it was difficult to establish who the CAMHS key-workers were, although K and his parent said that he saw at least two psychologists at CAMHS in addition to many other professionals and trainees. However, his AMHS key-worker

felt that the AMHS team had attempted to ensure continuity of key-workers. Case H also had two key-workers while with CAMHS, and described the second one as just *'filling in'* prior to the transition to AMHS. Case D had three AMHS key-workers due to changing teams three times. Case E was currently with her second AMHS key-worker due to the previous one leaving the Early Intervention team, and would soon be on her third upon transfer to a CMHT.

Medication

Despite medication being a significant predictor of transfer to AMHS (see section 3.4.3 *Predictors of achieving transition*), three of the 11 cases who were prescribed medication by CAMHS no longer took any. Two (B and C) had stopped taking medication because they did not like the side effects. B said *'it felt like I was being someone else'*. Case I had never taken any medication, despite it being prescribed for him, and having discussed its pros and cons with his CAMHS key-worker. However, in most cases, particularly those with serious and enduring mental illness, the young people continued to take medication regularly (A, D, E, F, G, J & K). As one key-worker said,

'...I think there are parts of him that tolerates us, he thinks I've gotta take my medication because if I don't they'll be on my back...' (G's AMHS key-worker)

Service user F felt that too much emphasis was placed on medication at adult services and noted the lack of contact with the psychiatrist at AMHS as compared to CAMHS. She mentioned that she saw the AMHS psychiatrist for just 10 minutes at a time and that the conversation focused just on medication. Similarly, the key-worker for C said that C was *'never overly keen to see the consultant psychiatrist'* because the appointment did not deal with emotional and social issues, just medication and assessment.

In a few cases, service users had a change in medication and diagnosis following transition. Service user D said that the medication was being changed because her mental health was declining:

'I've been feeling quite low so and it's becoming hard to snap out of it so they've increased the meds and I'm taking them, that's still not really helping so they'll probably change them again because they've changed them recently. They'll probably change them and if they don't change them the only option would be for them to put me on antidepressants but right now I'm taking as much meds as I can and trying whatever they've gotta give me just so I don't go on antidepressants because that's a quick trigger for me to become elated and go high so and if I do have to take antidepressants I will have to take them in hospital because, so they can monitor me closely.'

Case E's medication had been changed due to her changed diagnosis from schizophrenia in CAMHS to schizoaffective disorder within AMHS. Her key-worker noted that it *'took a while to get her on the right type of medication'*. Similarly, F's medication was changed following transition and both F and her parent felt that it was more effective. K was originally

prescribed '*medication for OCD and anxiety*' but, since a re-diagnosis of autism spectrum disorder, had been taken off it and started on '*an antidepressant*'. However, the AMHS key-worker stated that there had been no change in medication or dosage.

Optimal transition cases

Three of the four optimal transition cases from Stage 2 (i.e. at least one transition planning meeting, a period of parallel care, good information transfer, and engagement or appropriate discharge at 3 months post transition) were interviewed in Stage 4 (Cases B, D and G). For the most part, the interviews confirmed that these were examples of ideal transitions in relation to joint working, transition planning meetings, information transfer and engagement. However, other issues were brought up and there was some qualitative evidence that was incongruent with that obtained from the case note audit at Stage 2.

Case D and her key-worker both felt the transition from CAMHS to AMHS was as good as it could have been. Both, however, mentioned the stress of the additional transfer she had to make to another CMHT at a time when she was coping with an unplanned pregnancy, stopping her medication, and finding new accommodation, as these added additional pressure onto her. Following this she had another transfer to a different team and has also had involvement with Social Services professionals and a health visitor.

Case B and his mother both agreed that the transition to AMHS went well and that there was nothing that could have been done better, although his mother also emphasised that she did not want care to be transferred. She liked the care from CAMHS, had felt involved with his care and knew what was happening. She felt that B's mental health was deteriorating, and he was becoming suicidal. She became visibly upset during the interview, saying that she did not know to whom she should speak about her concerns. There was also some other incongruent data in this case. The mother said that the family had approached CAMHS directly, although case notes stated it was through a routine referral by GP. B said that he had stopped taking medication due to side effects while case notes indicated that he was still taking medication at the time of transition to AMHS.

Case G and his key-worker similarly both felt that transition had gone well, and could not think of anything else that could have been done better. G particularly appreciated that he was allowed to take his time making the transition with no pressure. There was also some incongruent data in this case. The AMHS key-worker said that there was no joint working, while case notes recorded a 10 week period of joint working.

G was referred to CAMHS at the age of 17. He explained that his family made him go to his General Practitioner (GP) as he was experiencing paranoia. The GP referred him to CAMHS, who then referred him to an inpatient unit. He has been diagnosed with a psychotic disorder.

G was an inpatient in a mental health unit for about four months, and describes this as a very negative experience. He thought the unit was under stimulating and did not trust the clinicians there. He felt trapped in a system in which he had to say he was mentally ill, even though he did not believe this, in order to leave. He said that if he had understood the 'system' more quickly and admitted he was mentally ill earlier on, he would have been allowed to leave sooner.

As the transition to adult mental health services approached, G recalls that his CAMHS key-worker told him he would soon have to transfer to another service. He was introduced to his AMHS key-worker a couple of times before the transfer and said the process allowed him to slowly move up to the adult services when he was ready. He felt that it was a good transition and commented that he did not 'notice it' much.

G has moved out of the family home and currently lives in supported accommodation. He speaks highly of the care workers there, finding them very supportive in practical ways. The care workers also meet with G and his AMHS key-worker regularly.

G finds AMHS less stressful than CAMHS because there are fewer meetings and his parents are not involved with his care. G appreciates that his parents are not told anything, and conversations are just between himself and his key-worker. He is well engaged with AMHS, although he is very mistrustful of mental health professionals, and says that he would not admit to them if he had a problem as it could result in him becoming an inpatient again. G says that he is not mentally ill, and there is no room in his life for mental health problems as he is busy with his education, friends, girlfriends and his family. He is taking a full-time course studying business.

5.3.4 The outcome of transition

Engagement

Most of the young people interviewed in Stage 4 were currently engaged with adult services (cases A, C, D, E, F, G, J and K). Despite often missing appointments, case C was well engaged with AMHS because her key-worker was flexible and followed up missed appointments as possible symptoms of decline in mental health. C commented that she appreciated being able to text her key-worker any time. Case J was also engaged with AMHS, but only attended for medication. K's mother felt that his attendance at AMHS was better than at CAMHS while his key-worker noted that he missed some of the appointments with the adult service made on his behalf by his mother.

'I haven't seen [J] for awhile but reading into him not coming to the appointments more recently I think he's probably found the different approach [between CAMHS and AMHS] difficult'.

Three young people (cases B, H and I) were no longer engaged with AMHS. B was discharged as his symptoms were resolved. H said she was no longer engaged with AMHS and did not want to be seen. Her CAMHS key-worker said that she had disengaged from CAMHS after a letter was sent offering assessment for psychotherapy by AMHS, and later disengaged completely from services. Case I was discharged from services due to non-attendance. He said he stopped going because he felt better and didn't like talking to a stranger and that he would only approach AMHS if he had a *'serious problem'*. His AMHS key-worker said that appointments had been set up at I's request but he wouldn't show up; she would telephone and send letters but eventually had to discharge him due to non-attendance. She said:

'...it was, very frustrating and difficult because I wanted to engage him and I knew how important it would be to, to try and make the transition to adult services as painless as possible so I, you know, I tried to word letters and speak to him in a way which, you know, would make him feel comfortable and stuff but I just, I couldn't find a way of really engaging him.'

Progression of mental illness

In many cases, young people felt that their mental health had improved since the transition to AMHS (cases A, B, C, G, E, H and I). Case I said that had he stopped going to AMHS as felt like he was getting better. His AMHS key-worker agreed that things were *'going really well'*. In contrast his mother felt that he continued to have mental health need as he could be *'suicidal'*.

Case A felt that his mental health was better but was unsure as to the reasons for improvement:

'...when I was at the CAMHS I hadn't really recovered properly but now I feel like I'm in a lot better state. Maybe it's just me that's changed, maybe the service at the CAMHS was good but where I wasn't recovered properly yet wasn't like, I wasn't responding to the care or anything like that but now it's a lot better.'

A's mother agreed:

'because he's off of drugs and he's taking his medication and he's a lot calmer. He still has his little flare-ups but on the whole nothing like what they were.'

Case B and his mother both felt that his mental state had improved since transition. C's mother said that she had seen improvement and self-awareness in C. Case G felt that he had no ongoing mental health problems:

'I go to school, my social life is good, girlfriends, my family life is good so I don't think there's any space for mental health problems but I know that I was paranoid [in the past].'

G's key-worker agreed that G's mental health had improved greatly since transition to AHMS, saying:

'he hasn't had any further relapses, he's had a couple of blips but nothing that's too worrying...when he first came to us he still did have quite a lot of paranoia which has eased a lot with time, I think that's credit to him, he's very good at thinking about things, working through some of the ideas he gets now.'

Case G's key-worker thought that transition to AMHS had been helpful for him and showed both progression and helped G's independence.

Even where users did not think they had a mental health problem, there was objective evidence of improvement following transition. While case E said:

'...I haven't anything wrong with me. I think it's people being superstitious and just saying things to make me believe and change my beliefs.'

her AMHS key-worker said that she was *'definitely stable now...and has become much better in the past year'*, avoiding hospital admissions despite having had some *'blips'*.

In 3 cases (D, F and K), there did not appear to be much change in mental health following transition, being neither better nor worse. Only one case (J) felt that his mental health had become worse since transition. He had suffered a relapse following transition and thought that this was due to a lack of counselling given by AMHS, although it appears that he was asking for early identification of relapse:

'...I think if I had a counsellor I would have been, I could have prevented it [the relapse] cause I could have told him exactly how I was feeling at the time and he could have, you know, started treating it then.' (J)

Interestingly his CAMHS case notes indicated that an unsuccessful attempt had been made to refer him to an Early Intervention service but that they were not accepting new cases at that time.

Education/employment

Out of the seven cases where employment and education were mentioned, four (A, C, D and I) were not in education or employment. D was a full-time mother to her young daughter. Case I said that he was *'struggling to find a job'*. C said that she wanted to return to employment or education. Two of the young people interviewed (E & G), both with an Early Intervention team, were successfully attending college courses despite having to drop out of education previously due to inpatient admissions. Case B, who had been discharged from AMHS following recovery, was currently studying full-time at university.

5.3.5 Other factors impacting on transition process and outcome

Our investigations revealed a number of other factors that complicated and impacted upon the success of the transition process.

Accommodation

Accommodation was mentioned in eight of the case studies. One case usually lived with his mother but at the time of transition was living in his car. Two others had always lived in the family home. Five of the young people interviewed had lived in supported accommodation at some point, and four of these had a serious and enduring mental illness. One of them had also spent over a year on and off as an inpatient while with CAMHS in between living in the family home. The others had all been living with family prior to moving to supported accommodation, which was usually precipitated by a rapid decline in their mental health, thus making it difficult for them and their families to live together. Two cases had left supported accommodation; one lived on her own and one was living with her partner and their child (service user D).

Pregnancy

Out of a total of five young women interviewed, three had unplanned pregnancies. One was pregnant at the time of interview (F), and one had had an abortion within the past year (C). For the third case (D), the pregnancy had a major influence on her mental health care since she had to leave her supported accommodation where pregnant women were not housed. She moved out of the catchment area of the AMHS she was with, even though she only moved a short distance from the supported accommodation and transferred to another AMHS team towards the end of her pregnancy. In addition to the stress of her pregnancy, moving home, and changing AMHS and key-workers, she stopped taking her medication due to the effect it could have on her unborn child. She did stay well throughout her pregnancy and went back on medication afterwards. However, soon after giving birth, D was transferred to yet another team within the new AMHS which offered more intensive support for her. Thus, in the space of four years, D moved three times, had four mental health key-workers, had several inpatient admissions (prior to pregnancy) and had Social Services involved. D said:

'Being with the adult mental health service is quite pressuring I find to be honest because there's too much transfers.'

Her former key-worker noted:

'...she's actually had lots and lots of different services in about a two, two and a half year period, which I think is probably really disruptive for her because during that period she's had so many hospital admissions as well and she's had lots of different people involved in her care.' (AMHS key-worker for D)

Physical health issues

Four young people had physical health issues, which were closely linked to their mental health. B has ongoing physiotherapy for physical disabilities, and had a transition from paediatrics to adult services. F had a premature birth, which her mother suspected was linked to her mental health problems. Case I has been in and out of hospital for several years due to asthma, as well as a transition from paediatrics to adult health. His parent spoke about negative experiences at hospital when he was admitted due to asthma problems, as well as when he was admitted to a mental health unit. C has diabetes and had several hospital admissions for this. Her parent and key-worker both hypothesised that her issues around managing diabetes were part of her mental illness and could be considered self-harm (she occasionally became very physically ill due to intentionally not taking her insulin). C had a transition from a paediatric to an adult diabetes service at age 16. Her mother noted that there was a 'gap' in diabetes service between 15 and 18 where *'they don't really know what to do with them'* and thought that both mental health and diabetes should transfer on to adult services at the age of 16. The staff at the diabetes clinic liaised well with both the CAMHS and AMHS key-workers, noted by both the parent and AMHS key-worker.

C was first referred to CAMHS at the age of 14 years but did not engage and was discharged. She was referred again at the age of 17 by her GP for depression. C was diagnosed with social anxiety, self-harm, low mood and an eating disorder. She has had diabetes for several years, and has been involved with a diabetes service during this time. The poor management of this illness led to the diagnosis of an atypical eating disorder. C has lived alone since the age of 16 as there was a lot of conflict in the family home where she lived with her mother and sister.

During her first CAMHS appointment at the age of 17, C was told that she would be transferred to adult services after a few months as she was close to her 18th birthday. Knowing she would soon be leaving, C did not 'open up' much to CAMHS workers and missed several appointments. C's CAMHS key-worker, as well as the other clinician she frequently saw, left shortly before C's transfer to adult services; C had never previously met the CAMHS worker representing her at her transition planning meeting. Although she liked the CAMHS workers involved in her care, in hindsight, C believes she should have been referred directly to AMHS.

Despite being well-engaged with AMHS, C is disappointed that she only occasionally sees a psychiatrist for assessments and to discuss medication. She hoped that AMHS would be more helpful than CAMHS, and provide a 'cure' for her problems through their adult approach and more access to psychiatrists. However, she feels that her mental health and her relationship with her mother has improved, and appreciates the flexibility and availability of her key-worker.

In addition to mental health and diabetes services, social services have also been involved with the family and C commented on how she was used to lots of meetings with doctors and repeating her 'life story'. On her 18th birthday, C was an inpatient in hospital because of complications of her diabetes. She had already experienced one transition due to being transferred from the paediatric to adult diabetes service at the age of 16.

In the past year, C has terminated an unplanned pregnancy. She is currently unemployed and not in education, but would like to get a job and is considering taking a course in social work.

Other services

Five of the young people interviewed also had involvement with other services at some point, including Social Services (C and D), health visitor (D, due to baby), Homeless Persons Unit (D), probation service (I), school/education support (K), counselling service (H) and autism support service (K) which was accessed via self-referral, rather than through CAMHS or AMHS. In two cases, these additional services were filling gaps not met by CAMHS or AMHS (autism support service for K and counselling service for H). The autism support service for K was found via self-referral by his

parent, and both K and his parent spoke highly of this (while speaking very negatively of the services they had received from CAMHS and AMHS).

These additional services were sometimes a cause of concern. K's parent described her frustration with how Social Services said autism was a mental health issue, and not their responsibility, while mental health services said it was a learning disability, and therefore under Social Services remit. C's mother described difficulties in dealing with Social Services and feeling like she was being stereotyped and scrutinised as a single mother. She expressed difficulties with doctors and seemed cynical of all services, saying that she had walked out of meetings before, even though she spoke highly of AMHS and her daughter's current key-worker. D noted that her baby was already on her second social worker and was yet only one year old. She also mentioned that Social Services, the health visitor and her care co-ordinator recently had a meeting about her without her knowledge, which she found distressing.

Inpatient admissions

Five of the young people interviewed had been admitted to an inpatient unit due to their mental illness at least once at some point, with the length of each admission ranging between one week and one year. Only one of them (A) found the admission helpful: *'I felt a lot better afterwards and it also helped me stop taking drugs'*. Others (D, E, G and I) all described their inpatient experiences negatively.

G felt that he was in hospital for too long and that *'the people in the hospital they try to keep you in and they don't stimulate you in any way'*. He was mistrustful of mental health professionals, seemingly from his inpatient experiences:

'... I'll never be open to any mental health professional like a doctor. If I had serious problems then I wouldn't be open to them because at the end of the day they can lock you up...'

E had three lengthy inpatient admissions: *'...it's like my life is being in hospital'*. She felt that the admissions were inappropriate and that with the right support she could have lived at home. She also said that she got bullied by staff and patients and felt like she was in *'prison'*. Case I and his parent said that he was both physically and mentally mistreated on the inpatient unit. His mother said that she had to argue with staff to be allowed to see him, and, upon him saying that he wanted to leave the unit, he was punched by a staff member, given a sedative that resulted in an allergic reaction, and was then rushed to the emergency department due to complications with his asthma. His inpatient admission was at the same time of his transition to adult services.

D also found her inpatient experiences negative, saying *'I've been in hospital where nurses are, you know, sat down sleeping or watching the telly or being on their phone and I've seen all of that and it's quite off-putting.'*

Other transfers

In several other cases there were additional transfers. Cases E and G would be transferred soon to a CMHT since their Early Intervention service keeps users only for three years. E's key-worker said that both adult services and users '*struggle*' with this as CMHTs are less involved with the service users. Her Early Intervention team was under pressure to transfer to the CMHT due to heavy caseloads, but the CMHT '*might be dragging their feet about it*'. Case A was also transferred to an Early Intervention Team from CAMHS prior to his transfer to a CMHT.

D was first diagnosed with bipolar affective disorder when she was 16 years of age. She cannot remember much about her initial symptoms and diagnosis, but said her aunt recognised the symptoms (due to other family members having the same illness) and took her to an Accident and Emergency Department (A&E). From A&E she was admitted to an inpatient unit under the Mental Health Act 1983. She has since had several inpatient admissions, both while with CAMHS and AMHS.

At the time she initially became ill D was living with her parents. Shortly before leaving CAMHS, she moved into supported accommodation, which was a Trust-wide service. During this time, she was transferred from CAMHS to adult services. Several months later, D had to move out of the supported accommodation due to an unplanned pregnancy. Consequently, despite only moving a short distance physically, she was no longer eligible to be seen by her AMHS team as she was now outside their catchment area. Her key-worker thus had to help D find new accommodation as well as arrange a transfer to another adult mental health team while D was reaching the end of her pregnancy. D's original AMHS key-worker noted that she stayed involved 'unofficially' via telephone for several weeks post-transfer because of all these changes. D's current AMHS required her to live in the catchment area for two years before she could attend, so in between the original and current AMHS, she was seen by a different service. Since moving to her current service, she has been transferred to an Early Intervention Team that can offer her more appropriate support.

D currently lives with her partner, who is also her carer, and their young child. She is unemployed and not in education. D and her partner are having relationship difficulties and he can sometimes be violent towards her. D feels frustrated at what she sees as a lack of support from AMHS in relation to these problems. D is visited regularly by Social Services and a health visitor due to concerns about the impact of her mental health problems on her parenting abilities. While her parents had attended a couple of CAMHS Family Therapy sessions and AMHS meetings, D chooses not to have them currently involved in her care. D was pleased to report that her mental health was stable throughout and after her pregnancy, despite stopping her medication and clinicians' concerns that she would relapse, although she did say that lately she had been feeling quite low due to a lot of stresses.

Within three years, D has experienced four mental health team transfers and key-workers, three changes of accommodation, several inpatient admissions, and the involvement of other services. In addition, she has set up a home with her partner and become a mother.

Waiting lists

Waiting lists were also raised as an issue during interviews, with several young people having to wait to receive treatment by mental health services. F had to wait about four months initially to be seen by CAMHS and another four or five months to be seen by AMHS. H was also on a waiting list for AMHS treatment and found this very negative, saying:

'...you're making them wait for so long, and I'm thinking well, people could be dead by that time and stuff so I didn't think it was very good but I know it's like not their fault if they've got like massive waiting lists and don't have many nurses, doctors and stuff.'

She was also put on a waiting list for AMHS psychotherapy prior to the transition; at this point she disengaged with CAMHS *'in anticipation of the work starting there'* according to her key-worker. K was told that there was a six-month wait to get psychological treatment (cognitive behavioural therapy) from AMHS but had been waiting twelve months to be seen. His key-worker, however, said the wait has been about six months. In addition, K's mother stated that there was a further delay in having contact with AMHS as the CAMHS key-worker mistakenly did not send a referral letter to adult services when she should have.

Two young people (C and K) felt that their expectations of adult services had not been met. C said that she expected AMHS to be a *'miracle cure'* as she had only been seen by counsellors and psychologists at CAMHS and thought seeing a psychiatrist would *'sort it out'*. Both K and his mother had unmet expectations of adult services:

'I felt that the adult team would be different...that help would be more constructive and positive'

His mother commented: *'I was pinning everything on this'*.

5.3.6 Respondent-generated suggestions for improvement in transition

Several interview participants had thoughts on how transition from CAMHS to AMHS could be improved. In most cases, they addressed the issue of age boundaries and joint working.

One parent felt that her son should have stayed with CAMHS beyond the age of 18 (B). One service user (C) felt she should have been referred directly to AMHS despite being only 17. Her parent suggested that physical health services, in this case a diabetes clinic, and mental health services should be aligned so that users get transferred to adult services at the same age. The key-worker for K commented on the age boundary for transition, noting that his service user *'is a very young 17. Unfortunately there's not a huge amount of flexibility...'*

The CAMHS clinician for H felt that a joint meeting with the service user and the AMHS team or a period of parallel care would have been helpful. The

clinicians interviewed for both cases I and C all suggested a longer period of joint working for both these cases. The AMHS clinician for K suggested joint meetings and a *'more flexible approach'* where CAMHS either referred earlier, or saw him after the age cut-off boundary so there was not a gap while he was on waiting list at AMHS.

A service specifically for adolescents/young adults was suggested by service user E's AMHS clinician, I's CAMHS clinician, and the parent of I. The key-worker for C and D said that she was hopeful that a designated link worker position between CAMHS and AMHS would be put into place by the trust, although this was unconfirmed at the time of the interview.

Both C and her parent said that a more holistic approach should be taken by all the services that are involved in a service user's care:

'...I just think that it was a complete waste of time going there and maybe these services, like GPs, mental health teams, all sort of thing, they should be a bit more in the loop together, you know? Not like so separate they don't know what's going on, the service providers, not really, I just think they should be a bit more knowledgeable of each others and what they offer and stuff like that and they should talk more, like what would be more beneficial to the patient because like I wouldn't like anyone else to like go through that really, you know, like, just go to one and then be passed on to the next one when you're eighteen. That's what it was like, it's like, oh, you're eighteen now, you gotta go...' (C)

5.4 Discussion

5.4.1 Issues and limitations

There were several problems in recruiting participants in Stage 4 interviews, with only 11 out of the planned 20 service users and 16 of the potential 60 clinicians and carers being interviewed. The most common reason was no response from the service users to the requests for participating (25%). All letters that were sent out that did not receive any response were followed up with either a phone call or a second letter. The second most common reason was that a clinician (usually the AMHS key-worker) deemed it clinically inappropriate for the service user to take part in the study (18%), most often due to the nature and/or severity of the illness at that time.

The importance of engaging young people with mental health problems both in research and service development or young people's participation projects is well acknowledged and a number of toolkits, guidance documents and exemplars are available (Badham and Wade, 2003; National CAMHS Support Service and YoungMinds, 2005; Street and Hertz, 2005). However, the difficulty of engaging young people and ensuring participation is only now starting to be acknowledged (Laws, 1998). Other projects have found that the sample of young people participating ended up being less varied and extensive than initially anticipated (e.g. Young Person's Advisory Service, 2007) and that serious difficulties are encountered in contacting young people to take part in any consultation process (Laws, 1998; National

CAMHS Support Service and YoungMinds, 2005). Even studies of routine outcome monitoring within CAMHS have noted how difficult it is to get responses from young people and their parents (Johnston and Gowers, 2005; Ford, Tingay and Wolpert, 2006).

In our experience getting a response from the appropriate person involved with care was often time-consuming, with days or even weeks passing before clinicians returned phone calls and faxes despite repeated attempts to contact them. In some cases, key-workers were no longer available, having left the team due to a new job or retirement, or they were on leave. A further delay was that some young people had been transferred from one AMHS team to another, which took days or weeks to establish, only to then start the process of contacting the new key-worker all over again. In a few instances, it was difficult to establish what AMHS team, if any, the service user was being seen by. In two of the cases we attempted to recruit, the AMHS team mentioned in the case notes denied all knowledge of the service user. Some case note information was incomplete and/or inaccurate, with key-worker details missing or AMHS team information being obsolete. Some AMHS teams were no longer in existence, having merged with others and several had changed locations. Table 23 shows the main reasons for failure of adequate recruitment.

Table 23. Recruitment issues

Reason for non-recruitment of service users	n	%
no response from service user	20	25.3%
clinically inappropriate	14	17.7%
no current contact with AMHS team or GP (discharged/did not engage/moved out of area)	11	13.9%
out of time to chase	11	13.9%
no response from clinician	8	10.1%
user declined to participate	5	6.3%
unable to establish AMHS team	5	6.3%
interview arranged but user did not attend	3	3.8%
user out of country	1	1.3%
user deceased	1	1.3%

Unsurprisingly, the majority of service users interviewed were those cases which had joint working between CAMHS and AMHS who were still engaged with services three months after transition. Tellingly, three of the four cases considered to have 'ideal transitions' (see section 3.5.2 *Optimal transitions*) were Stage 4 participants.

A further limitation was that in the interviews, some young people were not as articulate or forthcoming as others, and some clinicians were more informative than others. In these cases, analysis relied more on data taken from parent and/or clinician interviews. Laws (1998) has commented on the importance of allowing enough time to build up trust with young people.

However, research projects have to meet strict deadlines, with only a fixed amount of time for recruitment and data collection.

5.4.2 Transition experiences of service users, carers and mental health professionals

Haggerty *et al* (2003) state 'Continuity is not an attribute of providers or organisations. Continuity is how individual patients experience integration of services and coordination' (p1220). This section discusses the perceptions of service users, parents and professionals on transition as a process rather than mere transfer of care. It should, however, be noted that these interviews were undertaken in relation to those young people who were transferred from CAMHS to AMHS. The views of those who may have fallen through the gap are hence missing. Also, cases where service users failed to engage with AMHS or where there was no evidence of joint working are under-represented. Perhaps the views, experiences and outcomes of this group are even more important especially as they may later present in crisis and subsequent transitions may be qualitatively undermined by being unanticipated and hence unplanned (Coleman and Berenson, 2004; YoungMinds, 2006a).

While the main focus of the TRACK interviews was on the transition from CAMHS to AMHS, it became clear that this was not the only change that service users had experienced. A number of young people experienced multiple transitions between teams; staff turnover and service organisational changes also meant that they experienced changes in key-worker within services. Services, too, are constantly undergoing transition. These all affect continuity of care, especially relational continuity (Freeman *et al*, 2002), deleteriously. The cumulative effect of all these transitions was a complex and unsettling experience for many service users including moving out of parental home, relationship problems, being homeless or in supported accommodation, being pregnant or becoming physically unwell. This complexity has been noted previously in YoungMinds' 'Stressed Out and Struggling' report entitled *Two steps forward, one step back?* (Pugh *et al*, 2006) on 16-25 year olds' journeys into adulthood. The *Breaking the Cycle* report (Social Exclusion Unit, 2004) also found that 98% of young adults (16- to 25-year-olds) accessing services in the UK had more than one problem or need, which included homelessness, problems associated with leaving care, mental ill-health, lack of training/education opportunities, barriers to employment, crime, poor housing, drug and alcohol misuse and learning disability.

This complexity is reflected in the number of agencies involved with young people participating in this stage of TRACK. The multi-agency picture included supported accommodation agencies (five of the eleven young people interviewed had lived in supported accommodation at some point, and four of these were young people with serious and enduring mental illness); pregnancy-related services (3/5 young women in the sample) and physical health services at primary and secondary care (4/11) as well as Social Services, health visitors, a homeless persons unit, the Probation

Service, school/education support, a separate counselling service, an autism support service and an immigration service and detention centre. This reinforces the need for multi-agency transitions planning (Department for Education and Skills and Department of Health, 2006; Department for Children Schools and Families and Department of Health, 2008; Lamb *et al*, 2008), for general transitions as well as mental health transitions issues.

Young people who were on medication were identified as more likely to achieve transfer to AMHS by TRACK Stage 2. Medication was also an issue of concern raised at Stage 3. In Stage 4, however, we found that some young people on medication at the time of referral stopped their medication, some changed their medication and others expressed a dislike of any focus only on medication when seeing adult psychiatrists. Joint working and transition planning meetings were affected negatively by demand and capacity issues. Staff sometimes seemed to think that transition planning meetings were not necessary as the case was not complex or chaotic. However, such an approach does not take into account the views of the service user or carers who may still need transition planning, even though their situation is not highly complex.

Most of the young people interviewed were currently engaged with AMHS. In many cases, young people felt that their mental health had improved since transition to AMHS. Transitions between CAMHS and Early Intervention services appeared to work well. These are positive findings and reinforce the need for ensuring that all young people with a mental health problem who need transition should not only be appropriately referred, but that systems should be in place to ensure that few, if any, fall through any gaps in transitional care.

6 Discussion

'I just think that it was a complete waste of time going there [CAMHS] and maybe these services, like GPs, mental health teams, all sort of thing, they should be a bit more in the loop together, you know? Not like so separate they don't know what's going on, the service providers, not really, I just think they should be a bit more knowledgeable of each others and what they offer and stuff like that and they should talk more, like what would be more beneficial to the patient because like I wouldn't like anyone else to like go through that really, you know, like, just go to one and then be passed on to the next one when you're eighteen. That's what it was like, it's like oh you're eighteen now you gotta go...' – Service user

6.1 Introduction

The focus of TRACK has been specifically on mental healthcare (mental health service-specific) transition between CAMHS and AMHS. However we acknowledge that young people leaving CAMHS with ongoing mental health needs could have their some of these needs met elsewhere (within either statutory or voluntary services, self- or family/peer help providing groups). Young people and their families may have differing preferences and perspectives about their needs, the options for alternatives may vary (at individual, family/community and service levels) and not all young people leaving CAMHS will have what they perceive to be on-going mental health needs. By studying CAMHS to AMHS transition, we are not making value or outcome related judgements on alternatives that might be in the best interest of young people but have focussed on whether there is continuity of care between NHS mental health service providers, where CAMHS clinicians thought there was ongoing need.

Despite clinicians', parents' and policy makers' concerns about young people becoming 'lost' in the transition from CAMHS to AMHS, as evidenced in the qualitative interviews, there is paucity of research evidence about policies, process, outcomes and experiences of such transition in the United Kingdom (Forbes *et al*, 2002; Singh *et al*, 2005; HASCAS, 2006; Kennedy *et al*, 2007). Specific gaps exist in the evidence base on predictors and outcomes of successful transition and experiences of the process by users, carers and clinicians, together with an understanding of the organisational barriers and facilitators for transition. Such gaps provided the impetus for the TRACK study, which was designed with the overarching aims of identifying the organisational factors which facilitate or impede effective transition between CAMHS to AMHS and making recommendations about structure and delivery of services to promote good continuity of care.

Key findings to emerge from this four stage multi-centre, multi-method study are summarised for each stage as follows.

Stage 1: Mapping and content analysis of CAMHS to AMHS transition policies/protocols within mental health services in Greater London and the West Midlands:

Mapping transitional policies and procedures of CAMHS was complicated by size, structure, levels of specialism and place of CAMHS within NHS organisational units.

A total of 13 protocols in London and 3 in the Midlands sites were analysed; protocol sharing by CAMHS within and across trusts was variable.

Content analysis of protocols revealed little variation in underpinning principles which were largely based on National Service Frameworks.

However, protocols differed on several aspects of transition, including personnel involved in protocol development, transition boundaries, planning meetings, formal transition plans and joint working between CAMHS and AMHS. Only three protocols (all in Greater London) required the use of CPA as a criterion for transition.

Most protocols identified the service user as central to transition process.

None specified ways of preparing users for transition.

Three quarters of protocols had no provision for ensuring continuity of care for cases not accepted by AMHS.

All protocols considered an enduring mental health problem as an important criterion for referral to AMHS.

Estimated average annual numbers of cases successfully making transition in London ranged from 0-50 (mean 8.3; SD 9.5, n=33); no comparable information was obtained from West Midlands sites.

Stage 2: Quantitative evaluation of transition processes and outcomes:

A total of 154 cases were tracked, of which 90 (58%) were actual referrals and 64 (42%) were potential referrals. Potential referrals included anyone who crossed the transition boundary during the study period but did not make a transition to adult care because they were not referred to AMHS, were still being seen by CAMHS or were not accepted by AMHS.

Our rates of actual and potential referrals per 100,000 population in the London sites were 2.68 and 1.49 respectively, the corresponding figures for West Midlands sites were 2.23 and 2.97 respectively.

Of 64 potential referrals, 52 were not referred to AMHS primarily because of refusal by carer or service user (n=12, 23%), because CAMHS clinicians knew or thought that AMHS would not accept these referrals, (n=12, 23%) or because of no further clinical need (n=10, 19%).

AMHS accepted 93% of cases referred to them by CAMHS, challenging the widespread perception that AMHS are reluctant to accept such referrals.

Referrals to Early Intervention in Psychosis services always achieved transition.

Actual referrals were significantly more likely to have attended CAMHS with their parents.

Of 90 actual referrals, 63 were found to have had continuity of care, i.e. being engaged with AMHS 3 months post-transition or appropriately discharged.

Only four out of 90 actual referrals (4%) met the criteria for optimal transition defined as having continuity of care, at least one transition planning meeting involving the service user and/or carer, a period of joint working between CAMHS and AMHS, and optimal information transfer.

Age, accommodation (living on own), family history of mental health problems, looked after child, child protection involvement, parental attendance, admission, admitted under the mental health act, serious and enduring mental illness, eating disorder, substance misuse, emerging personality disorder, on medication and comorbidity were significantly associated with achieving transition in univariate analysis. Logistic regression demonstrated that hospital admission, serious and enduring illness, and being on medication were independent predictors of achieving transition.

Continuity of care was more likely for those cases where young people had married/cohabiting parents or a serious and enduring mental illness. Continuity of care was less likely for those with emotional/neurotic disorder or an emerging personality disorder.

Neurodevelopmental disorders such as ADHD and Asperger syndrome, and emotional/neurotic disorder cases were most likely to fall through the care gap between CAMHS and AMHS.

Stage 3: Evaluation of organisational cultures, structures, processes, and resources constituting barriers and facilitators which influence transition, derived from interviews with health and social care professionals and representatives of voluntary organisations.

Cultural philosophies differed between CAMHS and AMHS; the former was described as more person-centred, holistic and family-oriented, and the latter as medication- and crisis-oriented.

Facilitators for transition and continuity of care were dedicated transition posts, joint AMHS/CAMHS appointments/secondments, transition forums, co-working between psychiatrists/ care co-ordinators, early communication prior to transition, greater inclusivity of parents/carers in AMHS and management awareness of the need to provide services for ADHD and learning disability.

Barriers for transition and continuity of care were variability in eligibility criteria and thresholds between AMHS/CAMHS, communication problems, inconsistent use of documentation, different cultural philosophies between CAMHS/AMHS, lack of confidence for managing young people in AMHS, lack of two-way understanding and clarity about services between CAMHS and AMHS, limited funding for transition posts, high staff work/caseloads, lengthy waiting lists, lack of inpatient facilities and limited services for ADHD, autism spectrum disorder and mild to moderate learning disability.

Stage 4: Qualitative multi-perspective case studies of actual and potential transitions obtained from interviews with service users, parents/carers, CAMHS and AMHS clinicians, which describe transition experiences and the factors that promote and hinder successful transition.

Participants described three mechanisms for preparing users for transition: transfer planning meetings, periods of parallel care and information transfer. Very few service users or carers had experienced such preparation, and those that had viewed these as positive. Professionals attributed time pressures as an impediment to ensuring such preparation in cases needing transition.

Where the service user did not engage with AMHS, the parents had no involvement. Most young people preferred not having their parents involved in their care with AMHS, while parents wanted more involvement with AMHS.

Service user/carer accounts of transition varied in terms of timing, preparation, parental involvement, key-worker turnover/relationships and continuation of medication following transition.

Interviews with optimal transition cases (n=3) identified in Stage 2 confirmed that these were exemplars of ideal transitions regarding joint working, planning meetings, information transfer and post-transition engagement with AMHS.

Most service users who experienced transition to AMHS stayed engaged and reported improvement in their mental health.

Accommodation support, pregnancy, physical health issues, inpatient admissions, lengthy waiting lists and transfers involving several service teams/agencies all impacted on the process of transition in terms of complexity and outcome for the service user.

Respondent recommendations for improving transition included increased flexibility on age boundaries, greater alignment of mental health and physical health services, more joint meetings, the provision of specific services for young people, transition link worker appointments and a more holistic, integrated services approach to transition.

Key methodological issues:

Recruitment into the study was difficult at all sites, with response rate so poor from one site that it had to be abandoned. Clinicians, even while appearing enthusiastic about the research, were unable to participate as expected.

IT data sets, particularly in CAMHS, are poor quality and unable to provide clinical information in a robust and reliable manner.

The lack of central databases in mental health services and the poor quality of information available appear major impediments for both service evaluation and service development and should be a major cause of concern for service commissioners, planners and providers.

In this section, an integrated, triangulated synthesis of findings has been undertaken with the intention of providing a 'diagnostic analysis', illuminating the factors influencing transition and continuity of care between CAMHS and AMHS. Interpretation of findings is constrained by the previously acknowledged limitations of the different stages of TRACK, mainly around recruitment but also resulting from procedural delays caused by ethics and governance challenges, the impact of trust mergers and restructuring (West Midlands), poor participation from clinicians, service users and carers in some areas and variability of case note information.

6.2 Context of transition: service complexity and cultures

6.2.1 Service complexity

The complexity of mental health services that have to be negotiated during transition creates challenges even for health and social care professionals, who appear unfamiliar with the differences between CAMHS and AMHS, including use of terminologies, scope of professional roles and approaches to care management. Treasure *et al* (2005) reviewed different tiers within organisational structures and the links between them involved in transition. These encompass general practice, four tiers of CAMHS, paediatrics, secondary and tertiary adult psychiatric services, school and student services and Social Services. Findings of different stages of TRACK study confirm this complex interface between CAMHS to AMHS, which create barriers to transition and continuity of care.

Challenges encountered in the mapping of transitional policies (Stage 1) included huge complexity within CAMHS units which differed in their size, structure, levels of specialism and place within organisational units. No comprehensive map of CAMHS services was available in London and in both London and the West Midlands services had to be identified from multiple and varying sources of information. The absence of such vital service level information raises questions about awareness of professional staff relating to local organisational structures, services and the potential impact on channels of communication. Complexity also emerged in patterns of protocol sharing, notably where several protocols were shared by teams in a single trust, raising doubts about consistency of working, when the content of protocols was variable (see section 6.3 *Negotiating the transition boundary*).

It was not surprising therefore that interviews with CAMHS and AMHS staff (TRACK Stage 3) revealed a mutual lack of understanding and clarity on service availability. There clearly is a lack of two-way communication between CAMHS and AMHS in general, and around transition in particular. Young people in the study identified several other developmental and social transitions (such as moving accommodation) that they were experiencing at the same time as transition from CAMHS to AMHS. The CAMHS to AMHS transitional care process is ideally placed to address these multiple needs in a satisfactory manner and could mitigate some of the challenges experienced by these young people. This would however require, as an essential prerequisite, much closer liaison and communication between CAMHS and AMHS, currently clearly lacking, and multi-agency transition planning (e.g. with education services, social and housing services).

6.2.2 Service cultures

TRACK confirmed the presence of an ideological, conceptual, clinical and cultural divide between CAMHS and AMHS (Kipps *et al*, 2002; Singh *et al*, 2005; HASCAS 2006). In general, CAMHS takes a developmental perspective and is family focused. AMHS is perceived to be more 'medical'. Interviews with professionals and representatives of voluntary organisations (Stage 3) found that CAMHS was perceived as more person centred, family oriented and holistic, using 'talking therapies' more often. In contrast, AMHS were viewed as dealing with crises, medication and lacking confidence and skills to manage young people. Differences were also evident in approaches to joint working between CAMHS and AMHS (see section 6.4.1 *Joint working*). This resonated with findings from Stage 4, where users and carers also felt that AMHS care was focused on medication, psychiatrists dealt with medication but not emotional and social issues, there was a lengthy wait for psychological therapies, parents were not involved and felt 'left in the dark.'

These findings are not entirely surprising given that Stages 1 and 2 clearly demonstrated that an enduring mental health problem was an important criterion for referral from CAMHS to AMHS and enduring mental health problems and being on medication were significant predictors of transition. In Stage 4, most service users reported improved mental health following

transition to AMHS. Taken together this suggests that CAMHS needs to pay greater attention to biomedical approaches and AMHS to psychosocial interventions. The 'holistic CAMHS' versus the 'medical AMHS' are simplistic caricatures: good practice requires both services to adopt a holistic biopsychosocial approach. It is interesting to see that in services such as Early Intervention, which have tried to overcome these ideological divides, transition of care progressed more smoothly and was experienced as being more positive.

Differences in level of parental involvement in CAMHS and AMHS present an interesting clinical and ethical dilemma. A child mental health professional expects to see a child in the waiting room; an adult mental health professional, an adult. Families want greater involvement even after their child moves to AMHS; service users want lesser involvement from families as they develop autonomy and independence. Movement between these different cultures inevitably requires a process of adaptation by young people and their families. Common multidisciplinary training in adolescent health and transitional care may be one way forward to bridge cultural divides and develop good practice guidelines (McDonagh and Viner, 2006; Department for Children Schools and Families and Department of Health, 2008).

6.3 Negotiating the transition boundary

6.3.1 Policies and protocols

National Service Frameworks (Department of Health, 2003; Department of Health and Department for Education and Skills, 2004) and recent policy guidance (Department for Children Schools and Families and Department of Health, 2008) emphasise that transition should be a guided, educational and therapeutic process and stress the importance of transition protocols, pathways and care plans in achieving best practice linked to positive outcomes. Stage 1 found that while protocols identified factors important in ensuring smooth transition and reflected general policy principles, they differed in content. Important differences related to involvement of services/agencies involved in protocol development, definitions of transition boundary, procedures for service users not accepted by AMHS, information transfer, duration of transition planning, and whether the CPA care level was a criterion for transition.

The variable content of protocols and complex patterns of use within trusts raise questions regarding their utility and impact on practice. Our findings show that having a policy in place does not necessarily change or improve clinical practice; a policy-practice gap remains. In Stage 3 interviews professionals rarely, if ever, mentioned or referred to any transition protocols. Most protocols stated that service users and carers should be prepared for transition; none specified procedures or practice for achieving this. Stage 4 interviews with professional staff, service users and carers confirmed that service users and their carers were not adequately prepared for transition.

Protocols required, and professionals recognised the importance of joint planning meetings between CAMHS and AMHS involving the service user and carers. Many users included in Stage 4 had attended at least one such transition planning meeting. However, Stage 2 revealed that joint planning meetings did not take place in all cases. The planning and delivery of joint working or parallel care were very variable indeed. Some young people and parents in Stage 4 reported feeling very disappointed with the lack of preparation for transition, citing abrupt timing and short notice of the move to AMHS.

There were two policy and practice aspects of continuing care for young people which should raise serious concerns. Firstly, there is clear lack of policy about service users who reach the transition boundary, have ongoing needs but are either not referred to AMHS or not accepted by AMHS. This group includes users with neurodevelopmental disorders, emotional/neurotic disorders and emerging personality disorders, many of whom are on medication at the time of transition. They clearly fall through the CAMHS-AMHS gap. Secondly, protocols make no provision for ensuring that users referred to AMHS do actually engage with adult services. Care responsibility cannot and should not end at the point of making a referral. Given the high risk of disengagement during the transition process, it is surprising and worrying that protocols do not specify procedures to ensure that referred cases get engaged with care.

6.3.2 Eligibility criteria

Operation and impact of eligibility criteria: context

In Stage 3 professionals expressed high level of concern over differing thresholds and eligibility criteria between CAMHS and AMHS. In general, CAMHS were perceived as working with a 'different' user group, becoming involved at lower thresholds encompassing low mood, relationship difficulties and self-harming. In contrast, AMHS were perceived as operating at higher thresholds relating to serious mental illness (e.g. psychosis), forensic histories and those requiring inpatient admissions. Concerns were also expressed that it was difficult to transfer young people to AMHS when they were in a stable state following treatment; in other words, not in a crisis state. Resurgence at crisis points in adulthood has case management implications for service providers as well as potentially damaging consequences for young people beyond the transition phase. It is vital that young people can access services before any crises escalate (National CAMHS Review, 2008).

Overall, the perception was that AMHS were not meeting the needs of young people beyond those with chronic, serious and enduring conditions. Others with neurodevelopmental disorders, emotional/neurotic disorders and emerging personality disorders could not be transferred. This resulted in them being retained by CAMHS until early adulthood, or returned to the care of their GP. These findings resonate with those of Vostanis (2005) relating to the high rates of service users whose mental health needs fall into the gap between CAMHS and AMHS. These different thresholds and

eligibility criteria can clearly form barriers to flexible, long-term and cross boundary continuity during the process of transition.

In addition, both CAMHS and AMHS staff found the thresholds and eligibility criteria to be highly complex, bureaucratic and confusing. Many called for greater clarity, information and understanding of what is actually available to CAMHS staff looking to provide ongoing care, including services provided by voluntary organisations, Social Services, education and youth offender teams. The confusion also extends to and impacts both directly and indirectly on service users and their families, who are left uncertain about who is responsible for their care.

Service professionals suggested a number of potential solutions, including lowering eligibility thresholds, updating protocols, training AMHS staff to increase their confidence and capabilities in working with young people, and the creation of transitional worker posts to help staff navigate the boundaries between services. All these solutions have major resource implications. TRACK findings show that threshold and eligibility criteria are currently being rigidly interpreted in a way to reduce the caseloads of AMHS workers already struggling with complex and demanding work. These potential solutions therefore will require new resources - just newer ways of working may not do. However, our finding that only 4% cases that crossed over to AMHS had an optimal transition goes well beyond simply a resource issue. Our optimal transition criteria were not particularly onerous; and some basic good practice guidelines (see section 7: *Recommendations*) should improve the process, outcome and experience of transition without the need for major new resources.

Age

Recent policy guidance (Department for Children Schools and Families and Department of Health, 2008) and National CAMHS Review (2008) advocate flexibility in applying age-based transition criteria to ensure that varying needs in relation to the development of young people are met. Variable age criteria were highlighted as key findings impacting transition in Stages 1 and 3. Stage 1 revealed that age-based transition boundaries in protocols varied between 16 and 21 years and over, with a modal value of 18, suggesting a lack of consensus on this issue, although policy guidance requires CAMHS to be provided until the age of 18 years (Department of Health and Department for Education and Skills, 2004). All protocols, however, emphasized that transition could occur flexibly over a period of time dependent on individual needs; hence transfer between the CAMHS and AMHS service was not based solely on a service user's age.

However, in marked contrast to the flexibility emphasised in protocols, experiences of many CAMHS professionals (Stage 3) were that adult services often rigidly interpreted age criteria when transferring young people, to the extent of not accepting service users and therefore not arranging CPA meetings or discussing care options, until their actual birth date. This was seen as a form of protectionism for adult services staff driven by high caseloads and a lack of trained staff to meet demand. Others identified risk management issues in taking on young people before their

18th birthday, a lack of emergency care for young people approaching 17 years and some adult psychiatric consultants not accepting responsibility for young people aged below 17 years. In some cases CAMHS deliberately continued working with a young person after the service's upper age limit had been reached, to complete specific work or for young people needing long-term psychotherapy.

Many staff referred to the wide variability in service cut-off ages impacting decision-making about where to transfer young people, particularly where shared care might be required with other and multiple service providers, notably Social Services and education, leading to service providers avoiding responsibility and ownership of care. In contrast, voluntary and non-statutory agencies were perceived as working with much broader age ranges (often up to age 25) and being more flexible in whom they would accept. These findings suggest a need for much greater multi-agency working and involvement of universal services alongside CAMHS and other specialist services and have implications for service commissioning and workforce training (National CAMHS Review, 2008).

6.3.3 Diagnosis

National Service Frameworks (Department of Health, 2003; Department of Health and Department for Education and Skills, 2004) stress the need for young people to have access to age appropriate services respondent to need as they grow into adulthood and for service improvements to be achieved through addressing any gaps in service provision.

All four stages of TRACK confirmed that young people with severe and enduring mental health problems, in particular those with early psychosis referred to Early Intervention services, do make a transition to AMHS. However, a large group of young people with neurodevelopmental disorders such as ADHD and ASD, emotional/neurotic disorders and emerging personality disorder do not make a transition. Protocols in Stage 1 of TRACK identified 'an enduring mental health problem' as an important criterion for referral to AMHS. Findings of Stage 2 confirmed that that hospital admission, serious enduring illness and being on medication, were associated with achieving transition.

AMHS accepted the majority of referrals made to them, despite the misperception that they do not, leading to CAMHS clinicians to not even attempt to refer many cases. Many potential referrals – either refusing transition, or perceived as not needing a service, or not being referred or accepted – remained on medication and needed continuing support. In Stage 3 clinicians reported that those with neurodevelopmental, emotional and emerging personality disorders were retained and managed by CAMHS, signposted to voluntary services or returned to their GP. Lack of service provision for mild to moderate learning disability, ADHD, and ASD were the most frequently mentioned resource gap by all groups of professionals in all trusts and by non-statutory organisations, where demand was seen as rapidly growing with limited provision. The gap in provision was also recognised by trust managers, who were actively considering how to meet

this need, while acknowledging that adult services did not have the specialist skills needed. These dilemmas were starkly illustrated by the experiences of one young person (Stage 4) who had self-referred to a non-statutory autism support service after wrangling between CAMHS, AMHS and Learning Disability about whether autism was either a learning disability or a mental health problem. Inevitably, the impact of this on transition for the young person and family was negative.

Our findings confirm the concerns expressed by the Royal College of Paediatrics and Child Health (2003) that many young people with substantive and ongoing mental health needs are falling through the net of the health and social care systems due to gaps in service provision. The recent paper on good practice guidance by the Royal College of Psychiatrists (Lamb *et al*, 2008) recommends that specific agreement is reached between CAMHS and AMHS, reflected in protocols, regarding the transfer of care for young people in the diagnostic categories of ADHD, ASD, mild to moderate learning disability, emerging personality disorder, and that commissioners must be informed of gaps in services and responsibilities to commission new services where necessary. We endorse this, and also recommend a review of thresholds for transfer to AMHS and improvement in the skills and resource deficits in the AMHS workforce.

6.4 Crossing the transition boundary: optimal and suboptimal transition

Only four of the 90 actual referrals tracked in Stage 2 experienced an optimal transition, three of whom had a diagnosis of serious and enduring mental illness. For the majority of actual referrals who crossed the boundary, transition was suboptimal, raising questions relating to joint working and parallel care, information transfer, therapeutic relationships and continuing engagement of young people with the service over time.

6.4.1 Joint working

Although most protocols specified the need for at least one transition planning meeting, more than one third did not specify the need for a transition plan and the majority did not emphasise joint working and involvement of other agencies in transition planning or in development of protocols. The use of care pathway approaches, which would support joint working, was not identified in protocols or by professional staff. None of the protocols specified how service users should be prepared for transition. Some professionals reported a lack of two-way communication, lack of interagency working, lack of joint posts such as transition workers as major impediments to joint working. In some cases involvement of several different services during transition made the process very complex (see section 6.2 *Context of transition: service complexity and cultures*). Experiences of young people and parents suggested a variable approach to transition planning and joint working operated. For some, no period of parallel care or joint working had taken place and notification of transition could be short (as little as one month) or at the last or penultimate

appointment with CAMHS. This contrasted with many protocol recommendations of 3-6 months and those of the Royal College of Psychiatrists of a period of at least 6 months (Lamb *et al*, 2008).

In contrast, facilitators to joint planning included dedicated transition posts, joint appointments between CAMHS and AMHS, co-working between psychiatrists and care co-ordinators and transition forums, which were all facilitative for transition and cross boundary continuity. However, other approaches/service models have also been suggested as ways of overcoming the barriers identified above and achieving improvements in CAMHS to AMHS transition. These include the inception of 'virtual' teams (a collaboration of health professionals working in different areas but with a collective accountability for transition), where members of multidisciplinary CAMHS and AMHS teams work together to provide a range of skills and expertise to meet mental health needs of young people presenting to either service (Lamb *et al*, 2008) and the development of specialist services for young people aged 16-25 (Royal College of Nursing, 2004; YoungMinds, 2006a). Earlier reports by the Audit Commission (1999) and the NHS Advisory Service report *Together We Stand* (Health Advisory Service, 1995) also support the creation of adolescent mental health services as the best approach to address transition problems and ensure developmental and other age-related needs are met.

6.4.2 Information transfer

Facilitators for information transfer were the positive approaches to joint working described above by professionals. We found significant shortfalls in IT systems and central databases and poor cross-boundary communication between services. Less than half of protocols (46%) specified that a risk assessment and management plan should be transferred to AMHS. None specified what information should be provided to young people and families. Referrals from CAMHS to AMHS were mainly via letters written by key-worker or consultant psychiatrist or via central referral services. The latter has been acknowledged by professionals to be helpful in enhancing responsiveness and reducing emphasis on eligibility criteria, but unhelpful in establishing dialogue between key staff. Tracking of referrals on trust databases by researchers revealed a number of problems – either no databases were available or those in existence were of varying comprehensibility and accuracy – our conclusion was that current IT systems, particularly in CAMHS, do not allow managers to access high quality information on which to determine commissioning decisions and funding priorities. Information transfer was also hampered by a lack of understanding of each other's services by CAMHS and AMHS (see section 6.2 *Context of transition: service complexity and cultures*), use of inconsistent documentation, different systems used for transfer of electronic information and transfer of referrals to lengthy waiting lists during which professional dialogue was reduced. Inadequate IT systems in mental health services clearly hinder informational continuity (Burns *et al*, 2007). The recent National CAMHS Review (2008) also notes the frustrations that arise

as a result of separate, incompatible IT systems across different agencies and the need for systems reform and resource support.

6.4.3 Therapeutic relationships and family involvement

Transition is daunting for young people and carers – trusting therapeutic relationships are built over time with CAMHS, and there is uncertainty about AMHS. TRACK identified such anxieties among professionals, young people and their parents. Professionals reported feelings of loss and concerns about terminating therapeutic relationships with young people who anyway had difficulties in building trusting relationships. Transition planning meetings were considered helpful in allaying some parents' fears about transfer. Periods of parallel and joint working, supportive roles of transition workers and early preparations for transition which allowed time to establish new relationships were also seen as helpful, consistent with approaches advocated by the Royal College of Nursing (2004), McDonagh and Viner (2006), and Department for Children Schools and Families and Department of Health (2008).

Freeman *et al* (2002) defined relational, personal and therapeutic continuity as 'the need to provide one or more individual professionals with whom the service user can maintain a consistent professional relationship'. Key-workers are intrinsic to achieving such continuity. Interviews with young people confirmed that while some established positive relationships with key-workers, others had a more challenging time, finding different approaches between CAMHS and AMHS difficult. Several young people experienced changes in key-workers additional to that at the point of transition from CAMHS to AMHS. Reasons for this included changing teams on a number of occasions, turnover of professional staff and simultaneous involvements with several different services, all with key-workers. These are likely to be the 'depersonalised transitions' reported by Burns *et al* (2007) where service users feel that they are 'left dangling in unknown territory'; for some, the prospect of a change in key-worker was devastating.

Parental involvement has already been discussed in relation to differing cultures of CAMHS and AMHS (see section 4.3.4 *Perceived cultural difference between CAMHS and AMHS*). A very interesting finding was that parental attendance at CAMHS, and parental status (married or cohabiting) facilitated transition; having separated or divorced parents associated with lesser chance of being referred and greater likelihood of suboptimal continuity of care. In Stage 4, in cases where the service user did not engage with AMHS, the parents had no involvement. This possibly reflects both the influence of parental stability and active involvement of parents in advocacy prior to and during the transition process. On the whole, parents wanted more involvement with AMHS, feeling left out or having no point of contact with regard to their worries about their children. On the other hand, many young people preferred not having their parents involved in their care following transition to AMHS.

The balance between young people's rights and parents' and carers' rights has been mentioned in section 4 and the challenge of achieving the balance

is noted in a number of transitions related documents (Department for Education and Skills and Department of Health, 2006; McDonagh, 2006; Royal College of Physicians of Edinburgh Transition Steering Group, 2008). The recent National CAMHS Review (2008) notes the importance of services that support parents and carers and helps them secure the best outcomes for their children, given their central role in nurturing mental health and psychological well being; parents reported wanting to be able to support children more effectively. A simple but effective way of improving transitions for isolated young people or those without involved families might be to provide advocates who build a relationship with the young person over time and attend transition planning meetings.

Young people and parents indicated that they would like more choice, e.g. about things like whether to go straight to adult services rather than be seen for a few months at CAMHS, or to remain with CAMHS for longer. This coheres with the statements on transition in the recent CAMHS review (National CAMHS Review, 2008) that stresses that flexibility at times of transition to AMHS should be for developmental as well as choice reasons.

6.4.4 Engagement

A positive finding was that most AMHS made considerable efforts to engage young people referred to them. However, initial engagements were often protracted by lengthy waiting lists (reflecting staff shortages and eligibility issues) which were a source of frustration to young people and carers. Interviews with young people revealed that most were engaged with AMHS and had experienced an improvement in their mental health following transition to AMHS. Professionals reported that a flexible approach helped in following up missed appointments; young people indicated that lines of communication incorporating texting a key-worker to discuss appointments were very helpful in maintaining engagement.

It is important to remember that not all cases that were not referred to AMHS are necessarily failures. Adult mental health services may not be the right place for all young people, and by sometimes not referring CAMHS clinicians give young people the opportunity to leave mental health services. Additionally, CAMHS who do not refer on because they know the referral will not be accepted spare their clients the potential upset of being rejected in the referral process. This also gives clinicians time to prepare their clients for life without mental health services.

Some clinicians may find that mental health services are not in the best interest of their clients and the so-called 'natural' ending of CAMHS services at the age of 18 is an ideal time to discharge a young person who may not have been in need of such services anyway, possibly having been wrongly referred to CAMHS in the first place. Some young people's difficulties unexpectedly improved to such an extent that there was no longer a clinical need by the time they crossed the transition boundary.

Taken from the perspective of an adolescent or a parent, the discharge without being referred on could be seen as an achievement – take for instance the number of young people and parents who did not want to be

referred to adult services in Stage 2. A key area for future research would be the outcomes for young people who do not make the transition to adult services, and what impact this has had on them, as all those identified for the TRACK researchers were initially thought to have an ongoing clinical need.

7 Recommendations

'... there is a hope of saving them, but it all has to be done together, it's a total waste of money really because if one's doing one thing and the other's doing another they're not getting together to help the patient in any way really, she's getting told two completely different ways to live and not live so I think that should be maybe more put under one umbrella' – Parent of service user

7.1 Introduction: *mind the gap*

It is a paradox that while treatment for mental disorders in young people have improved substantially in the past two decades, health systems responses to young people with mental disorders have been inadequate (Patel *et al*, 2007). Although adolescence is a risk period for the emergence of serious mental disorders, substance misuse, other risk taking behaviours, and poor engagement with health care systems, mental health service provision is weakest during this stage of life (McGorry, 2007; Patel *et al*, 2007). By following a paediatric-adult split, mental health service boundaries introduce discontinuities in care provision where continuity is most needed. All four stages of TRACK confirm that for the vast majority of service users, transition from CAMHS to AMHS is poorly planned, poorly executed and poorly experienced. Mutual misperceptions among clinicians contribute to pre-existing ideological, practical and structural barriers between CAMHS and AMHS. In this section we explore possible solutions to the current problems of transitional care and make recommendations at several levels aimed at clinicians at the coal-face of care delivery, managers who plan local services, commissioners who fund and prioritise regional health care needs and national policy makers who drive top-down change.

In our view there are two basic and contrasting approaches to improving care for young people undergoing transition from CAMHS to AMHS. We can improve the interface between CAMHS and AMHS as they currently exist, or we can develop a completely new and innovative service model of integrated youth mental health services. Each has its own advantages, limitations and resource implications. Common to both approaches is the need for services to pay attention to the developmental needs of this age range (i.e. regarding concomitant education, social and legal changes). While we call for further research into ways of improving transitional care, TRACK findings by themselves demand early and substantial service improvement, some of which can occur without new resources but by simply improving liaison, planning and joint working between CAMHS and AMHS.

7.2 Improving the CAMHS/AMHS interface: *mind how you cross the gap*

The TRACK study found a misperception among CAMHS clinicians that AMHS are reluctant to accept those referred, inadequate preparation of service users for transition, poor information transfer from CAMHS to AMHS and little joint working between services during transition. Improvements in these areas can be achieved without substantial additional resources or service reconfiguration. For instance, in an age of email, improved communication could easily be achieved. Some might argue that TRACK highlights a failure to implement basic clinical procedures and optimal clinical practice. Attitudinal change is required, so that different services are seen as complementary rather than oppositional, and all are working for the common good for the service user. Clinging on to historical and outmoded differences in disease concepts, intervention strategies and

professional roles are outdated and unacceptable in an era of evidence-based practice.

Delineating the gap / aligning the thresholds:

TRACK suggests that counter to the perceptions of CAMHS professionals, AMHS accept the majority of referrals from CAMHS. While this might reflect reluctance of CAMHS professionals to refer those who they believe will be rejected, it obscures current gaps in provision. Where services exist, all young people with ongoing needs should be referred. Where they do not, such as services for neurodevelopmental disorders, these gaps and user needs should be systematically documented and made clear to commissioners. Local mapping of services should explicitly clarify service availability for young people (across agencies and sectors) and care pathways should be clarified in protocols developed through multi-agency collaboration. This will require that existing multi-agency management structures specifically address the needs of those requiring transition. Where such structures do not exist, these should be urgently developed. In addition, substantial improvements are needed in information systems to facilitate adequate monitoring of unmet need.

TRACK findings highlight that young people with emotional/neurotic, neurodevelopmental or emerging personality disorders are most likely to fall through the CAMHS-AMHS gap. The first and last of these groups may benefit from the drive to make psychological interventions more available (Layard, 2005) although concerns about achieving required numbers of skilled therapists remain. The picture for those with neurodevelopmental disorders is more complex, and there is an urgent need to develop skills in their management among staff working in AMHS (Asherson, 2005). Areas of controversy require further debate and study. These include the use of ADHD drugs, licensed only for children, in young adults (Nutt *et al*, 2006), and whether those with neurodevelopmental disorders would benefit from disorder-specific lifespan services. The British Association of Psychopharmacology concluded that services devoted to individual disorders may be inefficient 'in terms of capacity, skills and training' (Nutt *et al*, 2006, p32). Additionally, such services raise difficulties for individuals with comorbidity.

Prospective and longitudinal research is required to accurately describe the clinical course, service needs, health and social outcomes and cost implications for the young people who currently receive little mental health provision after leaving CAMHS.

Preparation of service users

Most transitions can be anticipated and hence there should always be an adequate period of planning and preparing the service user and their carer for transition. Information about adult services, what to expect, differences in service provision, CPA working, issues around confidentiality and parental involvement, etc., should all form part of a package of information that CAMHS share with service users and carers prior to transition. New or existing multi-agency forums should develop accurate and updated

information resources that describe what can be expected from adult services.

The process of transition

All transition-related work should focus on the needs of the service user (National CAMHS Review, 2008) rather than serve the rigid boundaries of services. To achieve this, services will have to develop flexibility in their approach. It is better to use 'age windows' in deciding the optimal point for transition rather than a rigid cut-off. In addition, a crisis should be a relative contra-indication to transition; transitions should only be planned and proceed at times of relative stability. There may be situations where transition can only occur during or immediately following a crisis, or where the transition process itself precipitates a crisis, but these occurrences should be relatively rare.

The completion of a transition logbook would be a cheap and simple intervention that might provide concrete and structured information about transition. It would be worked through with a key-worker(s) and could contain relevant details such as contact names and numbers, the dates and number of appointments with each agency, the final transition date and user views on the experience. This would provide a clear and concrete method of ensuring that the transition process was addressed. The impact of such tools on the process, outcomes and user experience should be clarified through audit and research.

Improving information transfer

Protocols for transition should explicitly specify information that should be transferred between agencies. Where possible, case-notes should follow the young person and detailed referral letters, including risk assessments, should be sent to AMHS to facilitate planning. Introduction of electronic records offers an opportunity to facilitate standardisation across services and trusts.

Improving liaison between CAMHS and AMHS

Generally, improved knowledge, communication and understanding between CAMHS and AMHS are required to facilitate collaborative working. This should be developed through joint training and continuous professional development regarding transition issues as well as modifications to service structure and functioning. Maitra and Jolley (2000) have described one such model where child and adult psychiatrists regularly attend each other's clinical meetings at which they jointly address the mental health needs of parents and children within families. Another approach has been the development of posts for family therapists who work part time in CAMHS and part time in AMHS to address the parenting needs of adult service users with children, who have been shown to be at increased risk for mental health difficulties and have high level of unmet need (Advisory Council on the Misuse of Drugs, 2003). TRACK found that designated transition workers with posts split between AMHS and CAMHS were highly successful in managing smooth transitions, and indeed transition worker posts are

recommended by Forbes *et al* (2001), HASCAS (2006), and the Social Exclusion Unit (2004). As pointed out by Maitra and Jolley (2000), such innovations have several benefits, including a higher profile for children within adult services, shaping of the process of referrals across services, improved scope for prophylactic work, possibilities of joint working and the availability of a forum for formal and informal discussions.

Improved knowledge, communication and understanding between services are inevitable; however, broad implementation of similar models will require development of an adequate workforce to fill these positions. Furthermore, skilful management of such posts is required to address concerns about clinical accountability, appropriate supervision, fragmentation of working practice and divided loyalties across teams.

Designated transition workers astride services

The TRACK findings suggest that, when available, transition workers were highly successful in managing smooth transitions between CAMHS and AMHS. Such specialised workers who are members of both child and adult services can potentially harvest the advantages of liaison models and joint working. However, there is a paucity of such staff with the necessary skills and a lack of training where existing staff may gain them. In areas where such posts have been created, such as Croydon in South London and in the West Midlands, these have later been lost in restructuring or under cost pressures. Unless skilfully managed, there may also be concerns about clinical responsibilities, supervision, fragmentation of working practice and divided loyalties across teams.

Boxes 3 - 8 provide lists of recommendations resulting from various TRACK findings. Overall these recommendations have specific implications for service providers in relation to improving existing services and future service developments. TRACK findings will hopefully also help commissioners when evaluating commissioned services and in their discussions with service providers about future innovations.

These strategies ultimately require closer collaboration between services and agencies. In times of fiscal austerity, it is difficult for clinicians to make a case for enhancing existing services or creating new posts such as transition workers or developing new services such as specialist clinics for adult ADHD. The CAMHS-AMHS split demonstrated in TRACK study is also mirrored in the differing commissioning arrangements whereby CAMHS are often commissioned by acute care or children's services commissioners while AMHS is firmly within the remit of mental health commissioners. In addition, at individual PCT level, the numbers of problematic transitions may be too low for this to be considered a priority by commissioners. However commissioning is and will remain a major lever for service redesign and improvement. Findings such as from the TRACK study are the best way for evidence to determine policy and shape both provision and commissioning of services. We therefore believe that joint commissioning between children and mental services and shared commissioning approaches at a regional level are the best ways to improve transitional care.

Box 3. Overall recommendations from TRACK

1. The needs of the service user should be central to protocol and service development regarding transition.
2. Trusts should have regular updated mapping of local CAMHS, AMHS and voluntary services, identifying scope of operation, communication networks and key contacts.
3. Protocols should be developed and implemented in collaboration with all relevant agencies and young people and their carers.
4. Multi-disciplinary training should be planned and delivered about transition, including local service structures, protocols, and working with young people. This training should be linked to the appraisal process and skills and competency frameworks.
5. Protocols should specify the time-frame, lines of responsibility and who should be involved, how the young person should be prepared and what should happen if AMHS are unable to accept the referral.
6. Protocols should stress flexibility in the age range to accommodate a range of needs and developmental stages, and have explicit referral criteria and service provision.
7. Transition should occur at times of stability where possible; young people should not have to relapse in order to access a service.
8. Agencies should try to avoid multiple simultaneous transitions.
9. Improved information transfer between CAMHS / AMHS with the standardisation of record keeping or, where this is impossible, clear indication of what information should be made available. A referral letter summarising past contact, current state and risks is a bare minimum. If all records cannot be transferred, copies of all correspondence and contact summaries should be.
10. Transition process should include collaborative working between CAMHS and AMHS, with cross agency working or periods of parallel care.
11. Carers' needs and wishes should be respected in the transition process and carer involvement in adult services should be sensitively negotiated between clinicians, service users and their carers.
12. Services need to develop for young people with emotional/neurotic, emerging personality and neurodevelopmental disorders wherever there is gap in such provision.
13. Active involvement by AMHS is required before CAMHS can discharge a case; transfer onto a long waiting list is unacceptable.
14. Changes should be evidence-based. Prospective research is required on the clinical course, service needs, health and social cost implications for the young people receiving little service provision after leaving CAMHS.

Box 4. Developing / implementing a transition protocol

1. This should involve all relevant agencies and practitioners working at the interface.
2. Ensure that key stakeholders are signed up for implementing the protocol.
3. Audit protocol implementation on a regular basis.
- 4 Protocols should be specific, i.e.:
 - give clear timeframes for preparation of the service user and the handover date
 - be clear in how the service user will be prepared for transition
 - be specific on who should attend transition planning meetings and handover of care meetings, and when these should take place
 - include a contingency and risk management plan including clarification of clinical responsibility during the transition process.
5. Ensure that procedures exist to identify service users who are not accepted by AMHS; or those service users who are not referred to AMHS but who have continuing needs (data should be routinely collected on numbers and needs of those in this category).
6. Annually update locality mapping of regional CAMHS, AMHS and voluntary services, identifying scope of operation, communication networks and key contacts.
7. Continuing professional development (CPD) for CAMHS, AMHS and other professional staff should include transition related issues
8. Develop local transition pathways (which give the protocol operational detail) and identify a lead person to take this forward.

Box 5. Preparing service user for transition

1. Aim to transfer service users in a planned fashion, not at crisis points – allow for flexibility depending on individual needs.
2. Take full consideration of other age related transitions and how these will impact, e.g. education transfer, housing moves, i.e. try to co-ordinate across sectors/ agencies so that young person not having to transfer everything at once.
3. Make service user and family aware of the potentially different resources and interventions available in CAMHS and AMHS.
4. Explain reasons behind the transfer and ensure that the service user and family have time to understand and discuss them.
5. Give written information to the service user and parent/carer describing AMHS and the transition process.

6. Ensure that transition planning covers areas important to the service user as these may not be the areas of primary concern to practitioners.
7. Make the service user aware of when they can expect to transfer to AMHS as soon as they begin attending CAMHS.

Box 6. Strategies for joint working

1. Ensure that both CAMHS and AMHS staff are committed to and understand the importance of joint working.
2. Representatives from both CAMHS and AMHS, including current and future key-workers whenever possible, must attend transition planning and handover of care meetings.
3. There should be consistent documentation of transition within and between CAMHS and adult services.
4. Continuous professional development to develop understanding of how teams work across AMHS and CAMHS. This could include brief secondments to neighbouring team e.g., one week or one day a week over a few weeks.

Box 7. Information transfer

1. Ensure that mental health services are linked in and share information with other agencies that may be transferring around the same time (i.e. physical health services, education, social care).
2. Try to avoid multiple simultaneous transitions by liaison with other agencies. Staggering CAMHS / AMHS transitions to avoid changes in key-worker and school / college / employment occurring all within the same month is likely to promote smoother transitions for all.
3. Ensure CAMHS sends a full written case summary and case notes (or copies of case notes, particularly correspondence and contact summaries), to AMHS, in advance of the transition planning meeting. If shared electronic service user records are used all necessary information should be available on that system.
4. Have clear documentation in the service user's record when transition is discussed, by whom and when.

Box 8. Ensuring continuity of care

1. Avoid service user being placed on waiting list – if service user will be placed on a waiting list at AMHS, then CAMHS should continue to provide services until they can be seen regularly.
2. Implement transition worker posts to work at the interface between CAMHS, AMHS and local voluntary agencies with a mental health remit.

3. For those service users who do not have parents attending CAMHS, have a responsible adult involved in transition whenever possible to advocate and provide support.
4. Consider collecting regular feedback from those who have experienced transition on their view of the process.

7.3 Developing a youth mental health service: bridging the gap

Some adolescent services are already being developed in the UK. For example, in 2005 the Department of Health funded the development and piloting of an Intensive Community Outreach Service (ICOS) within CAMHS in Solihull, West Midlands to provide assertive community support as an alternative to hospitalisation for young people with severe mental illness. Part of the service remit was to manage transition to AMHS. The service had a dedicated transition worker but this post was lost because of funding pressures. However, the service has successfully incorporated CPA principles in case management, developed transition strategies in liaison with local AMHS, and provides joint working with AMHS to ensure seamless transition. The initial success of ICOS has led to the provision becoming mainstream within CAMHS (www.csip.org.uk/silo/files/solihull-nsf-initiative-evaluation.pdf).

The Early Intervention in Psychosis model has been instrumental in overcoming some of the barriers between CAMHS and AMHS. EI services extend the holistic approach of CAMHS into AMHS, while the disease-specific focus of AMHS allows young people to get the best possible evidence-based care from highly trained staff. Two large randomised controlled trials, the LEO trial in London (Craig, Garety, Power, Rahaman, Colbert, Fornells-Ambrojo and Dunn, 2004) and OPUS in Denmark (Petersen, Jeppesen, Thorup, Abel, Øhlenschläger, Christensen, Krarup, Jørgensen and Nordentoft, 2005) have confirmed that early intervention services improve patient outcomes, promote engagement and increase service satisfaction. Such an early intervention approach can benefit a range of other mental health problems which are also embedded in disruptive developmental trajectories and social deprivation (see Medical Journal of Australia, 2007, suppl 7). TRACK findings confirm that transition from CAMHS to EI services is usually well managed and experienced as positive by service users. Melbourne in Australia and Birmingham in the UK have been at the forefront of the early intervention movement. Both areas are also heralding the youth mental health service model.

In Melbourne, the ORYGEN service is aiming to provide care to young people, aged 12–25 years, with emerging, potentially severe or complex mental disorders, especially psychoses, mood, personality and substance use disorders (McGorry, 2007). A range of community-based services are planned including triage and assessment services, extended hours multidisciplinary teams providing intensive community-based treatment, mobile youth-intensive case management services for young people with

complex needs, psychosocial interventions for users and carers, specialist disorder-specific services for young people with severe personality disorders, mood disorders and psychoses, comorbidity clinics, consumer and carer peer-support programs, and comprehensive recovery programs. Specialised youth inpatient units form an essential central element of this model.

In Birmingham an emerging Youth Mental Health programme provides mental health care for young people aged 14 and over. It has at its heart a public health ethos to reach out to young people in a culturally diverse city to improve mental health awareness and build resilience in young people. The service is organised around community projects that are bound together by their youth oriented website (www.wheres-your-head-at.com). The service is designed to be fronted by the early detection team ('ED:IT') which can provide prompt assessment and can link young people into streams of care including: Early Intervention in Psychosis teams; ADHD and Asperger syndrome; eating disorders; and depression. A specialised team manages transitions from CAMHS and focuses on the specific needs of 16- and 17-year-olds who have available dedicated youth admission facilities, including a secure setting for those with very challenging presentations. The psychosis stream works in partnership with Birmingham CAMHS (provided by Birmingham Children's Hospital NHS Foundation Trust) offering community outreach management of young people 14+, with shared responsibility under an agreed protocol.

In their review of youth mental health services across the world, Patel *et al* (2007) concluded 'our single most important recommendation is the need to integrate youth mental health programmes, including those in the health sector (such as reproductive and sexual health) and outside this sector (such as education)'. TRACK findings, while strongly endorsing this recommendation, also highlight how far away we are from such integration, given the problems of transition revealed at the interface of CAMHS and AMHS. Even though we do not as yet know how to achieve best transitional care, the *status quo* of existing service barriers should no longer be acceptable. We certainly need evidence for any models of transitional care that we test in the future, but the search for that evidence should be a goal, rather than a prerequisite without which change to existing service structure is not initiated. We need to ensure that the vital need for improving youth mental health is not ignored for fear of dismantling longstanding but increasingly unhelpful service barriers.

Even if services are reorganised in this fashion, the results of TRACK suggest that service users are almost inevitably going to experience subsequent and possibly frequent changes in services if they have ongoing mental health needs. Any change can be unsettling, and while not explicitly studied in TRACK, it is likely that its lessons could usefully be applied to transfers between AMHS teams or between AMHS and care of the elderly mental health team. However, studies of transition between other teams might highlight particular issues that do not occur when young people transfer between CAMHS and AMHS. TRACK provides evidence to suggest that policy on transitions for young people with mental health problems

should not be seen separately from those with physical health problems or those with disabilities. Finally, any changes to service structure or function should be evidence-based, with interventions studied rigorously to ensure that they do actually provide improvements to young people's mental health and experience of transition.

References

- Adair CE, McDougall GM, Beckie A, Joyce A, Mitton C, Wild CT, *et al.* 2003. History and measurement of continuity of care in mental health services and evidence of its role in outcomes. *Psychiatric Services* 54: 1351-1356.
- Adair CE, McDougall GM, Mitton CR, Joyce AS, Wild TC, Gordon A, *et al.* 2005. Continuity of care and health outcomes among persons with severe mental illness. *Psychiatric Services* 56: 1061-1069.
- Advisory Council on the Misuse of Drugs. 2003. *Hidden harm - responding to the needs of children of problem drug users*. London: Home Office.
- American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians-American Society of Internal Medicine. 2002. A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics* 110: 1304-1306.
- American Psychiatric Association. 2000. *Diagnostic and Statistical Manual of Mental Disorders (4th edition, Text Revision)*. Washington, D. C.: American Psychiatric Association.
- Asherson P. 2005. Clinical assessment and treatment of attention deficit hyperactivity disorder in adults. *Expert Review of Neurotherapeutics* 5: 525-539.
- Audit Commission. 1999. *Children in mind: child and adolescent mental health services*. London: Audit Commission.
- Badham B, Wade H. 2003. *Hear by right: standards for the active involvement of children and young people (revised edition)*. Leicester: National Youth Agency and Local Government Association.
- Belling RI, Whittock M, McLaren S, Burns T, Catty J, Rees Jones I, *et al.* 2008. Achieving continuity of care: facilitators and barriers in community mental health teams. *British Medical Journal* (Submitted).
- Beresford B. 2004. On the road to nowhere? Young disabled people and transition. *Child: Care, Health and Development* 30: 581-587.
- Bindman J, Johnson S, Szmukler G, Wright S, Kuipers E, Thornicroft G, *et al.* 2000. Continuity of care and clinical outcome: a prospective cohort study. *Social Psychiatry and Psychiatric Epidemiology* 35: 242-247.
- Blum R, Garell D, Hodgman C, Jorissen T, Okinow N, Orr D, *et al.* 1993. Transition from child-centered to adult health-care systems for adolescents with chronic conditions: a position paper for the Society of Adolescent Medicine. *Journal of Adolescent Health* 14: 570-576.
- Bosanquet NK, Kruger D. 2003. *Strong foundations: building on NHS reforms*. London: Centre for Policy Studies.
- Budd T, Sharp C, Mayhew P. 2003. *Offending in England & Wales: First Results from the Crime and Justice Survey*. London: Home Office.
- Burke R, Spoerri M, Price A, Cardosi AM, Flanagan P. 2008. Survey of primary care pediatricians on the transition and transfer of adolescents to adult health care. *Clinical Pediatrics* 47: 347-353.
- Burns T, Catty J, Clement S, Harvey K, Jones IR, McLaren S, *et al.* 2007. *Experiences of continuity of care and health and social outcomes: the*

- ECHO study*. London: National Coordinating Centre for Service Delivery and Organisation.
- Cabinet Office. 2007. *Reaching out: think family*. London: Cabinet Office: Social Exclusion Task Force.
- Cameron L, Murphy J. 2002. Enabling young people with a learning disability to make choices at a time of transition. *British Journal of Learning Disabilities* 30: 105-112.
- Chanen AM, Jackson HJ, McCutcheon LK, Jovev M, Dudgeon P, Yuen HP, *et al.* 2008. Early intervention for adolescents with borderline personality disorder using cognitive analytic therapy: randomised controlled trial. *The British Journal of Psychiatry* 193: 477-484.
- Children's Commissioner for England. 2007. *Pushed into the shadows: young people's experience of adult mental health facilities*. London: The Office of the Children's Commissioner.
- Coleman EA, Berenson RA. 2004. Lost in transition: challenges and opportunities for improving the quality of transition of care. *Annals of Internal Medicine* 141: 533-536.
- Commission for Health Improvement. 2003. *Transition of care between CAMHS and adult services*. www.chi.nhs.uk.
- Conway SP. 1998. Transition from paediatric to adult-oriented care for adolescents with cystic fibrosis. *Disability and Rehabilitation* 20: 209-216.
- Cooper C, Bebbington P. 2006. Mental health. In: Bajekal M, Osbourne V, Yar M, Meltzer H (ed.), *Focus on Health*. London: Office for National Statistics.
- Cosgrave EM, Yung AR, Killackey EJ, Buckby JA, Godfrey KA, Stanford CA, *et al.* 2008. Met and unmet need in youth mental health. *Journal of Mental Health* 17: 618-628.
- Cowlard J. 2003. Cystic fibrosis: transition from paediatric to adult care. *Nursing Standard* 18: 39-41.
- Craig TKJ, Garety P, Power P, Rahaman N, Colbert S, Fornells-Ambrojo M, *et al.* 2004. The Lambeth Early Onset (LEO) Team: randomised controlled trial of the effectiveness of specialised care for early psychosis. *British Medical Journal* 329: 1067-1070.
- Crawford MJ, de Jonge E, Freeman GK, Weaver T. 2004. Providing continuity of care for people with severe mental illness: a narrative review. *Social Psychiatry and Psychiatric Epidemiology* 39: 265-272.
- Crawford TN, Cohen P, First MB, Skodol AE, Johnson JG, Kasen S. 2008. Comorbid Axis I and Axis II disorders in early adolescence: outcomes 20 years later. *Archives of General Psychiatry* 65: 641-648.
- CSIP Choice and Access Programme. 2006. *Our choices in mental health - a framework for improving choice for people who use mental health services and their carers*. London: Care Services Improvement Partnership.
- Davis M. 2003. Addressing the needs of youth in transition to adulthood. *Administration and Policy in Mental Health* 30: 495-509.
- Davis M, Geller JL, Hunt B. 2006. Within-state availability of transition-to-adulthood services for youths with serious mental health conditions. *Psychiatric Services* 57: 1594-1599.

- Davis M, Sondheimer DL. 2005. State child mental health efforts to support youth in transition to adulthood. *Journal of Behavioral Health Services & Research* 32: 27-42.
- Davis M, Vander Stoep A. 1997. The transition to adulthood for youth who have serious emotional disturbance: Developmental transition and young adult outcomes. *Journal of Mental Health Administration* 24: 400-427.
- Department for Children Schools and Families, Department of Health. 2007. *A transition guide for all services: key information for professionals about the transition process for disabled young people*. <http://www.everychildmatters.gov.uk/files/TransitionGuide.pdf>.
- Department for Children Schools and Families, Department of Health. 2008. *Transition: moving on well. A good practice guide for health professionals and their partners on transition planning for young people with complex health needs or a disability*. London: Department of Health.
- Department for Education and Skills. 2004. *Every child matters: change for children*. London: Department for Education and Skills.
- Department for Education and Skills, Department of Health. 2006. *Report on the implementation of standard 9 of the national service framework for children, young people and maternity services*. London: Department of Health.
- Department of Health. 1995. *A handbook on child and adolescent mental health*. London: Department of Health.
- Department of Health. 1999a. *Effective care co-ordination in mental health services: modernising the care programme approach - a policy booklet*. London: Department of Health.
- Department of Health. 1999b. *National service framework for mental health: modern standards and service models*. London: Department of Health.
- Department of Health. 2000. *The NHS plan: a plan for investment, a plan for reform*. London: HMSO.
- Department of Health. 2001. *Valuing people: a new strategy for learning disability for the 21st century*. London: Department of Health.
- Department of Health. 2002a. *Improvement expansion and reform: the next three years' priorities and planning framework 2003-2006*. London: Department of Health.
- Department of Health. 2002b. *Mental health policy implementation guide: adult acute inpatient care provision*. London: Department of Health.
- Department of Health. 2003. *Getting the right start: national service framework for children: emerging findings*. London: Department of Health.
- Department of Health. 2006a. *Best research for best health: a new national research strategy*. London: Department of Health.
- Department of Health. 2006b. *Child and Adolescent Mental Health Service Mapping*. www.camhsmapping.org.uk.
- Department of Health. 2006c. *Good transitions for good people*. London: Department of Health.
- Department of Health. 2006d. *Transition: getting it right for young people*. London: Department of Health, Child Health and Maternity Services Branch.

- Department of Health. 2007. *Mental health act 2007*. London: Department of Health.
- Department of Health, Department for Education and Skills. 2004. *National service framework for children, young people and maternity services*. London: Department of Health, Department for Education and Skills.
- Department of Health, Institute of Psychiatry, Rethink. 2006. *Sharing mental health information with carers: pointers to good practice for service providers: NCCSDO briefing paper*. London: National Coordinating Centre for Service Delivery and Organisation.
- Dixon L, Adams C, Lucksted A. 2000. Update on family psychoeducation for schizophrenia. *Schizophrenia Bulletin* 26: 5-20.
- DOH. 2000. *Framework for the assessment of children in need and their families*. London: Department of Health, Department for Education and Employment and Home Office.
- Eiser C. 1993. *Growing up with a chronic disease*. London: Jessica Kingsley.
- Farrington DP. 1994. Early developmental prevention of delinquency. *Criminal Behaviour and Mental Health* 4: 209-227.
- Fonagy P, Target M, Cottrell D, Phillips J, Kurtz Z. 2000. *A review of the outcomes of all treatments of psychiatric disorder in childhood: MCH 17- 33- final report to the NHS Executive*.
<http://www.doh.gov.uk/research/mch/studies/execsum17-33.htm>.
- Forbes A, While A, Ullman R, Lewis S, Mathes L, Griffiths P. 2002. *A multi-method review to identify components of practice which may promote continuity in the transition from child to adult care for young people with chronic illness or disability*. www.sdo.lshtm.ac.uk.
- Ford T, Goodman R, Meltzer H. 2003. The British child and adolescent mental health survey 1999: the prevalence of DSM-IV disorders. *Journal of the American Academy of Child and Adolescent Psychiatry* 42: 1203-1211.
- Ford T, Hamilton H, Meltzer H, Goodman R. 2008. Predictors of service use for mental health problems among British school children. *Child and Adolescent Mental Health* 13: 32-40.
- Ford T, Tingay K, Wolpert M. 2006. CORC's survey of routine outcome monitoring and national CAMHS dataset developments: a response to Johnston and Gower. *Child and Adolescent Mental Health* 11: 50-52.
- Fortney J, Sullivan G, Williams K, Jackson C, Morton SC, Koegel P. 2003. Measuring continuity of care for clients of public mental health systems. *Health Services Research* 38: 1157-1175.
- Freeman G, Shepperd S, Robinson I, Ehrich K, Richards S. 2000. *Continuity of care: report of a scoping exercise for the SDO programme of NHS R&D*. London: National Coordinating Centre for Service Delivery and Organisation.
- Freeman G, Weaver T, Low J, de Jonge E, Crawford M. 2002. *Promoting continuity of care for people with severe mental illness whose needs span primary, secondary and social care: a multi-method investigation of relevant mechanisms and contexts*. London: NCCSDO.
- Galatzer-Levy RM. 2002. Created in others' eyes. *Adolescent Psychiatry: Developmental and Clinical Studies* 26: 43-72.

- Garland AF, Lewczyk-Boxmeyer CM, Gabayan EN, Hawley KM. 2004. Multiple stakeholder agreement on desired outcomes for adolescents' mental health services. *Psychiatric Services* 55: 671-676.
- Gergen KJ, Lightfoot C, Sydow L. 2004. OTHER ARTICLES: Social construction: vistas in clinical and adolescent psychology. *Journal of Clinical Child and Adolescent Psychology* 33: 389-399.
- Gillam T, Crofts M, Fadden G, Corbett K. 2003. *The interfaces project report: exploring the links between mental health services for children, adults and families*. NIMHE, NHS, The Meriden West Midlands Family Programme.
- Gillett G. 1999. *The mind and its discontents*. Oxford: Oxford University Press.
- Goodman R. 2005. *Child and Adolescent Mental Health Services: Reasoned Advice to Commissioners and Providers*, in Maudsley Discussion Paper no 4. London: King's College.
- Gowers SG. 2003. The future of inpatient child and adolescent mental health services. *The British Journal of Psychiatry* 183: 479-480.
- Green H, McGinnity A, Meltzer H, Ford T, Goodman R. 2005. *Mental health of children and young people in Great Britain, 2004. A report for the Office of National Statistics*. Hampshire: Palgrave Macmillan.
- Haggerty JL, Reid RJ, Freeman GK, Starfield BH, Adair CE, McKendry R. 2003. Continuity of care: a multidisciplinary review. *British Medical Journal* 327: 1219-1221.
- Harpaz Rotem I, Leslie D, Rosenheck RA. 2004. Treatment retention among children entering a new episode of mental health care. *Psychiatric Services* 55: 1022-1028.
- HASCAS.2006. *HASCAS: CAMHS to adult transition. HASCAS tools for transition. A literature review for informed practice*. London: Health and Social Care Advisory Service.
- Health Advisory Service. 1995. *Together we stand: the commissioning, role and management of child and adolescent mental health services*. London: Her Majesty's Stationary Office.
- Health Select Committee. 2000. *Provision of NHS Mental Health Services*. London: The Stationery Office.
- Humphrey C, Ehrich K, Kelly B. 2002. *Policies affecting human resource management in the NHS and their implications for continuity of care*. London: National Coordinating Centre for Service Delivery and Organisation.
- Information Centre for Health and Social Care. 2008. *CAMHS dataset consultation*. www.ic.nhs.uk/services/datasets/current-consultations/camhs.
- James A, Prout A. eds. 1997. *Constructing and reconstructing childhood*. 2nd ed. London: Falmer Press.
- Johnson S, Prosser D, Bindman J, Szmukler G. 1997. Continuity of care for the severely mentally ill: concepts and measures. *Social Psychiatry & Psychiatric Epidemiology* 32: 137-142.
- Johnston C, Gowers S. 2005. Routine outcome measurement: a survey of UK Child and Adolescent Mental Health Services. *Child and Adolescent Mental Health* 10: 133-139.

- Joyce AS, Wild TC, Adair CE, McDougall GM, Gordon A, Costigan N, *et al.* 2004. Continuity of care in mental health services: toward clarifying the construct. *The Canadian Journal of Psychiatry* 49: 539-550.
- Kendell R, Jablensky A. 2003. Distinguishing between the validity and utility of psychiatric diagnoses. *American Journal of Psychiatry* 160: 4-12.
- Kennedy A, Sloman F, Douglass JA, Sawyer SM. 2007. Young people with chronic illness: the approach to transition. *Internal Medicine Journal* 37: 555 - 560.
- Kent RM, Chamberlain MA. 2004. Transition from paediatric to adult neurological services: comment. *Journal of Neurology, Neurosurgery & Psychiatry* 75: 1208.
- Kessler RC, Chiu WT, Demler O, Walters EE. 2005. Prevalence, severity, and comorbidity of 12-month DSM-IV disorders in the National Comorbidity Survey Replication. *Archives of General Psychiatry* 62: 617-627.
- Kim-Cohen J, Caspi A, Moffitt TE, Harrington H, Milne BJ, Poulton PJ. 2003. Prior juvenile diagnoses in adults: developmental follow back of a prospective longitudinal cohort. *Archives of General Psychiatry* 60: 709-717.
- Kipps S, Bahu T, Ong K, Ackland FM, Brown RS, Fox CT, *et al.* 2002. Current methods of transfer of young people with Type 1 diabetes to adult services. *Diabetic Medicine* 19: 649-654.
- Knapp M, Perkins M, Beecham J, Dhanasiri S, Rustin C. 2008. Transition pathways for young people with complex disabilities: exploring the economic consequences. *Child: Care, Health & Development* 34: 512-520.
- Ko B, McEnery G. 2004. The needs of physically disabled young people during transition to adult services. *Child: Care, Health and Development* 30: 317-323.
- Kurtz Z, Street C. 2006. Mental health services for young people from black and minority ethnic backgrounds: the current challenge. *Journal of Children's Services* 1: 40-49.
- Lamb C, Hall D, Kelvin R, Van Beinum M. 2008. *Working at the CAMHS/Adult Interface: Good practice guidance for the provision of psychiatric services to adolescents/young adults. A joint paper from the Interfaculty working group of the Child and Adolescent Faculty and the General and Community Faculty of the Royal College of Psychiatrists, May 2008.*
- Laugharne R, Priebe S. 2006. Trust, choice and power in mental health: a literature review. *Social Psychiatry and Psychiatric Epidemiology* 41: 843-852.
- Laws S. 1998. *Hear me! Consulting with young people on mental health issues.* London: Mental Health Foundation.
- Layard R. 2005. *Mental health: Britain's biggest social problem?* No. 10 Strategy Unit Seminar on Mental Health, London: Prime Minister's Strategy Unit.
- Lee N. 2001. *Childhood and society: growing up in age of uncertainty.* Buckingham: Open University Press.
- Lotstein DS, McPherson M, Strickland B. 2005. Transition planning for youth with special health care needs: results from a national survey of children with special health needs. *Pediatrics* 115: 1562-1568.
- Ma K. 2005. Personality and attachment in adolescence. *The British Journal of Psychiatry* 186: 541-542.

- Maitra B, Jolley A. 2000. Liaison between child and adult psychiatric services. In: Reder P, McClure M, Jolley A (ed.), *Family Matters: Interface Between Child and Adult Mental Health*. London: Routledge.
- Malek M, Joughin C, Eds. 2004. *Mental health services for minority ethnic children and adolescents*. London: Jessica Kingsley Publishers.
- Margo J, Dixon M, Pearce N, Reed H. 2006. *Freedom's orphans: raising youth in a changing world*. London: Institute for Public Policy Research.
- McDonagh JE. 2006. *Growing up ready for emerging adulthood: an evidence base for professionals involved in transitional care for young people with chronic illness and/or disabilities*. Cambridge: Eastern Region Public Health Observatory.
- McDonagh JE, Kelly DA. 2003. Transiting care of the pediatric recipient to adult care givers. *Pediatric Clinic of North America* 50: 1561-1583.
- McDonagh JE, Viner R. 2006. Lost in transition? Between paediatric and adult services. *British Medical Journal* 332: 435-436.
- McGorry P. 2007. The specialist youth mental health model: strengthening the weakest link in the public mental health system. *Medical Journal of Australia (supplement)* 187: s53-s56.
- Medical Journal of Australia. 2007. *Supplement 7: Early intervention in youth mental health*.
www.mja.com.au/public/issues/187_07_011007/contents_011007_suppl.html.
- Mental Health Foundation. 1999. *Bright futures: promoting children and young people's mental health*. London: Mental Health Foundation.
- Miles K, Edwards S, Clapson M. 2004. Transition from paediatric to adult services: experiences of HIV-positive adolescents. *AIDS Care* 16: 305-314.
- Mottaghypour Y, Woodland L, Bickerton A, Sara G. 2006. Working with families of patients within an adult mental health service: development of a programme model. *Australasian Psychiatry* 14: 267-271.
- Muuss RE. 1996. *Theories of adolescence*. 6th ed. New York: McGraw-Hill.
- Myers F, McCollam A, Woodhouse A. 2005. *National programme for improving mental health and well-being: addressing mental health inequalities in Scotland - equal minds*. Edinburgh: Scottish Development Centre for Mental Health.
- National CAMHS Review. 2008. *Children and young people in mind: the final report of the National CAMHS Review*. Department for Children, Schools and Families and Department of Health.
- National CAMHS Support Service, YoungMinds. 2005. *Exploring participation in CAMHS: improving the Involvement of Children, Young People and their Carers in CAMHS*. CAMHS National Conference, Stratford: Leicester, Northampton & Rutland Strategic Health Authority.
- NHS Centre for Reviews and Dissemination. 1999. Getting evidence into practice. *Effective Health Care* 5: 1-16.
- Nutt DJ, Fone K, Asherson P, Bramble D, Hill P, Matthews K, et al. 2006. Evidence-based guidelines for management of attention-deficit/hyperactivity disorder in adolescents in transition to adult services and in adults: recommendations from the British Association for Psychopharmacology. *Journal of Psychopharmacology* 21: 10-41.

- O'Herlihy A, Worrall A, Banerjee S, Jaffa T, Hill P, Mears A, *et al.* 2001. *National inpatient child and adolescent psychiatry study (NICAPS): final report to the Department of Health*. London: Royal College of Psychiatrists' Research Unit.
- Office for National Statistics. 2002. *Census 2001: first results on population for England and Wales*. London: Office for National Statistics.
- Office for National Statistics. 2004. *Labour force survey*. London: Office for National Statistics.
- Onyett S. 2003. *Team working in mental health*. London: Palgrave.
- Patel V, Flisher AJ, Hetrick S, McGorry P. 2007. Mental health of young people: a global public-health challenge. *The Lancet* 369: 1302-1313.
- Paul M, Berriman JA, Evans J. 2008. Would I attend child and adolescent mental health services (CAMHS)? Fourteen to sixteen year olds decide. *Child and Adolescent Mental Health* 13: 19-25.
- Perkins R. 2001. What constitutes success? The relative priority of service users' and clinicians' views of mental health services. *British Journal of Psychiatry* 179: 9-10.
- Petersen AC, Leffert N. 1995. Developmental issues influencing guidelines for adolescent health research: a review. *Journal of Adolescent Health* 17: 298-305.
- Petersen L, Jeppesen P, Thorup A, Abel M-B, Øhlenschläger J, Christensen TØ, *et al.* 2005. A randomised multicentre trial of integrated versus standard treatment for patients with a first episode of psychotic illness. *British Medical Journal* 331: 602-608.
- Phimister D. 2004. *CAMHS/Adult transition pilots evaluation report stage 1*. NIMHE West Midlands Mental Health Development Centre.
- Por J, Golberg B, Lennox V, Burr P, Barrow J, Dennard L. 2004. Transition of care: health care professionals' view. *Journal of Nursing Management* 12: 354-361.
- Pugh K, McHugh A, McKinstrie F. 2006. *Two steps forward, one step back? 16-25 year-olds on their journey to adulthood (SOS: stressed out and struggling)*. London: YoungMinds.
- Reder P, McClure M, Jolley A, Eds. 2000. *Family matters: interfaces between child and adult mental health*. New York, NY, US: Routledge.
- Reid GJ, Irvine MJ, McCrindle BW, Sananes R, Ritvo PG, Siu SC, *et al.* 2004. Prevalence and correlates of successful transfer from pediatric to adult health care among a cohort of young adults with complex congenital heart defects. *Pediatrics* 113: e197-e205.
- Reiss J, Gibson R. 2002. Health care transition: destinations unknown. *Pediatrics* 110: 1307-1314.
- Reyna V, Farley F. 2006. Risk and rationality in adolescent decision making. *Psychological Science in the Public Interest* 7: 1-44.
- Richards M, Vostanis P. 2004. Interprofessional perspectives on transitional mental health services for young people aged 16-19 years. *Journal of Interprofessional Care* 18: 115-128.
- Ritchie J, Spencer L. 1994. Qualitative data analysis for applied policy research. In: Bryman A, Burgess R (ed.), *Analysing Qualitative Data*. London: Routledge.

- Roberts RE, Attkisson CC, Rosenblatt A. 1998. Prevalence of psychopathology among children and adolescents. *American Journal of Psychiatry* 155: 715-725.
- Rolison MR, Scherman A. 2002. Factors influencing adolescents' decisions to engage in risk-taking behavior. *Adolescence* 37: 585-597.
- Rosen DS. 2004. Transition of young people with respiratory diseases to adult health care. *Paediatric Respiratory Reviews* 5: 124-131.
- Rossi A, Amaddeo F, Bisoffi G, Ruggeri M, Thornicroft G, Tansella M. 2002. Dropping out of care: inappropriate terminations of contact with community-based psychiatric services. *British Journal of Psychiatry* 181: 331-338.
- Royal College of General Practitioners. 2002. *Getting it right for teenagers in your practice*. London: Royal College of General Practitioners/Royal College of Nursing.
- Royal College of Nursing. 2003. *Adolescent transition care*. London: RCN Publications.
- Royal College of Nursing. 2004. *Adolescent transition care*. London: RCN Publications.
- Royal College of Paediatrics and Child Health. 2003. *Bridging the gaps: healthcare for adolescents*. www.rcpsych.ac.uk.
- Royal College of Physicians of Edinburgh Transition Steering Group. 2008. *Think transition: developing the essential link between paediatric and adult care*. Edinburgh: Royal College of Physicians of Edinburgh.
- Royal College of Psychiatrists. 2002. *Acute inpatient psychiatric care for young people with severe mental illness: recommendations for commissioners, child and adolescent psychiatrists and general psychiatrists*. London: Royal College of Psychiatrists.
- Royal College of Psychiatrists. 2008. *Factsheet 16: Parental mental illness: the problems for children: for parents and teachers*. www.rcpsych.ac.uk.
- Rutter M. 1989. Isle of Wight revisited: twenty-five years of child psychiatric epidemiology. *Journal of the American Academy of Child and Adolescent Psychiatry* 28: 633-653.
- Sawyer SM, Drew S, Yeo MS, Britto MT. 2007. Adolescents with a chronic condition: challenges living, challenges treating. *The Lancet* 369: 1481-1489.
- Scottish Executive. 2003. *The mental health (care and treatment) (Scotland) Act 2003*. Edinburgh: Scottish Executive.
- Scottish Executive. 2005. *Children's and young people's mental health: a framework for promotion, prevention and care*. Edinburgh: Scottish Executive.
- Scottish Executive. 2006. *Delivery for mental health*. Edinburgh: Scottish Executive.
- Select Committee on Health. 2000. *Fourth report: provision of NHS mental health services*. London: The Stationery Office.
- Silva PA. 1990. The Dunedin multidisciplinary health and developmental study: a 15 year longitudinal study. *Paediatric & Perinatal Epidemiology* 4: 96-127.

- Simmonds S, Coid J, Joseph P, Marriott S, Tyrer P. 2001. Community mental health team management in severe mental illness: a systematic review. *British Journal of Psychiatry* 178: 497-502.
- Singh SP. 2000. Running an effective community mental health team. *Advances in Psychiatric Treatment* 6: 414-422.
- Singh SP, Evans N, Sireling L, Stuart H. 2005. Mind the gap: the interface between child and adult mental health services. *Psychiatric Bulletin* 29: 292-294.
- Singh SP, Grange T. 2006. Measuring pathways to care in first-episode psychosis: a systematic review. *Schizophrenia Research* 81: 75-82.
- Singh SP, Greenwood N, White S, Churchill R. 2007. Ethnicity and the Mental Health Act 1983. *The British Journal of Psychiatry* 191: 99-105.
- Singh SP, Paul M, Ford T, Kramer T, Weaver T. 2008. Transitions of care from child and adolescent mental health services to adult mental health services (TRACK study): a study of protocols in Greater London. *BMC Health Services Research* 8: 1-7.
- Smith K, Leon L. 2001. *Turned Upside Down: Developing Community-based crisis services for 16-25 year olds experiencing a mental health crisis*. London: Mental Health Foundation.
- Social Exclusion Unit. 2004. *Breaking the cycle*. London: Office of the Deputy Prime Minister.
- Social Exclusion Unit. 2005. *Transitions: young adults with complex needs*. London: Office of the Deputy Prime Minister.
- Sroufe LA. 1990. Considering normal and abnormal together: the essence of developmental psychopathology. *Development and Psychopathology* 2: 335-347.
- Street C, Hertz B. 2005. *Putting participation into practice - a good practice guide for practitioners working in services to promote mental health and wellbeing of children and young people*. London: YoungMinds.
- Tantam D. 2005. Pathways into adult care. *Psychiatry* 4: 141-144.
- The Children's Commissioner for England. 2007. *Pushed into the shadows: young people's experience of adult mental health facilities*. London: The Office of the Children's Commissioner.
- The National Assembly for Wales. 2001. *Child and adolescent mental health services: everybody's business*. Cardiff: The National Assembly for Wales.
- Treasure J, Schmidt U, Hugo P. 2005. Mind the gap: service transition and interface problems for patients with eating disorders. *The British Journal of Psychiatry* 187: 398-400.
- Tyrer P, Coombs N, Ibrahimi F, Mathilakath A, Bajaj P, Ranger M, *et al.* 2007. Critical developments in the assessment of personality disorder. *The British Journal of Psychiatry* 190: s51-s59.
- UKCRC Advisory Group for Connecting for Health. 2007. *UKCRC Advisory Group for Connecting for Health: The Report of the Research Simulations*. London: UK Clinical Research Collaboration.
- United Nations. 1989. *Convention of the Rights of the Child*. Geneva: Office of the United Nations High Commissioner for Human Rights.

- Viner RM, Barker M. 2005. Young people's health: the need for action. *British Medical Journal* 330: 901-903.
- Vostanis P. 2005. Patients as parents and young people approaching adulthood: how should we manage the interface between mental health services for young people and adults? *Current Opinion in Psychiatry* 18: 449-454.
- Vostanis S, Richards V. 2002. *Transition services for 16-19 year olds*. Leicester: Leicester University.
- Webster C, Simpson D, MacDonald R, Abbas A, Cieslik M, Shildrick T, *et al.* 2004. *Poor transitions: social exclusion and young adults*. Bristol: The Policy Press.
- Westen D, Dutra L, Shedler J. 2005. Assessing adolescent personality pathology. *The British Journal of Psychiatry* 186: 227-238.
- While A, Forbes A, Ullman R, Lewis S, Mathes L, Griffiths P. 2004. Good practices that address continuity during transition from child to adult care: synthesis of the evidence. *Child: Care, Health and Development* 30: 439-452.
- World Health Organisation. 1992. *The ICD-10 classification of mental and behavioural disorders*. Geneva: World Health Organisation.
- Young Person's Advisory Service. 2007. *Time to talk...time to listen: a consultation with Liverpool mental health service users aged 14-25*. Liverpool: Young Person's Advisory Service.
- Young S, Toone B. 2000. Attention deficit hyperactivity disorder in adults: clinical issues: a report from the first NHS clinic in the UK. *Counselling Psychology Quarterly* 13: 313-319.
- YoungMinds. 2006a. *A call to action: commissioning mental health services for 16-25 year-olds (SOS: stressed out and struggling)*. London: YoungMinds.
- YoungMinds. 2006b. *Emerging practice: examples of mental health services for 16-25 year-olds*. London: YoungMinds.

Appendix 1: Mapping Tool

TRACK Study: Service Evaluation Questionnaire

The TRACK study aims to explore the process of transition from Child & Adolescent Mental Health Services (CAMHS) to adult mental health services in London, Coventry and North and South Warwickshire. We specifically want to identify the organisational factors that facilitate or impede effective transition of patients from CAMHS to adult mental health services. We want to understand how services plan transition, how the process is implemented and what problems, if any, are perceived by those undergoing transition.

The study is funded by NHS Service Development and Organisation Research and development programme (SDO). No group or individual will be making any commercial or financial gain from it. The Wandsworth Research Ethics Committee (MREC) has reviewed the study and has given it their approval.

As an initial step, we are mapping current service provision. We would be very grateful if you could spend a few moments to fill the enclosed questionnaire.

All data will be treated in the strictest confidence. Your team will not be identified in any database and the data will not be used for any purpose other than the mapping exercise.

For the purpose of this study, *a service is defined as provider agency that provides CAMHS tier 2/3/4 services with shared transition protocols and procedures.* If within your service, some teams use different protocols or procedures for transition, please count each group of teams using a shared transition procedure/policy/protocol as a distinct service.

If you have any queries, comments or suggestions, please contact :

Dr Zoebia Islam Tel: 024 7657 5882, E-mail: z.islam@warwick.ac.uk

or

Prof. Swaran P Singh :Tel: 024 76150190, E-mail: s.p.singh@warwick.ac.uk

Many thanks for your help

Date _____

Team ID Number _____

(for office use only)

1. Team name _____

2. Respondent

Name: _____

Profession: _____

Job Title: _____

3. Catchment population000**4. Service type:**☐

CAMHS

Assertive Community Team

Adolescent

☐

Service

☐

Other specialist service (please specify) _____

5. Staffing levels: Total FTE equivalent (Full Time =1.0; for part time, each half day= 0.1)

Total mental health care staff (excluding trainees)		
	Total FTE per discipline	Total FTE at Consultant grade
Nursing		
Psychology		
Psychiatry		
Social work		
Systemic Psychotherapy/		

Family Therapy		
Psychodynamic Psychotherapy		
Experiential Psychotherapy, e.g. Art Therapy		
Child Primary Mental Health Practitioner		
Occupational Therapy		
Other (please specify)		
Other (please specify)		
Other (please specify)		

6. Case load: What is your team's caseload?

A case is defined as 'a young person with whom your service has been actively working. Active work includes any of the following activities: assessment, treatment, case management, liaison, consultation, case support and health promotion. The length of time spent with a case is not important.'

Numbers referred in the last calendar year _____

Number of currently open cases _____

(The last calendar year will be taken as January 1st - December 31st 2006)

7. Adult teams: How many adult teams does your service relate to and/or transfer cases to?

CMHTs _____ Eating Disorders _____

Learning Disability _____ Psychotherapy _____

Forensic Services _____

Others (please specify)

8. Transition boundary: How do you define the boundary between your service and adult services (that is, the criteria for referral on to the adult service)?

Age limit _____ Educational status _____

Other _____

Please give details:

.....

.....

.....

.....

.....

9. Transition numbers: How many patients stay within the service after crossing the transition boundary?

Please state the average number per year over the last three years _____

10. Closure policy: Do you have a written closure policy? ☐ Yes ☐ No

If yes, please attach a copy.

11. Transition protocol: Do you have a written policy/guidelines for transition of patients under your care to adult services? ☐ Yes ☐ No

If yes, please attach a copy.

12. Transition management: Do you have a written policy/guideline for managing the interface (i.e. the point at which interaction occurs) between your service and adult services?

Yes ☐ No ☐

If yes, please attach a copy.

13. Potential referrals: How many cases on average do you consider to be suitable for transfer to adult services?

Please state the average number per year over the last three years _____

14. Referrals accepted: How many cases on average make a transition from your service to adult services?

Please state the average number per year over the last three years _____

15. Transition Process: for patients making a transition, do you aim for?

(a) Documented hand-over planning

Always	
Sometimes	
Never	

(b) Joint meeting with adult service

Always	
Sometimes	
Never	

(c) Involvement of the parents/carers in care plan and decision making

Always	
Sometimes	
Never	

(d) Involvement of the service users in care plan and decision making

Always	
Sometimes	
Never	

Always	
Sometimes	
Never	

(f) Accountability for the process (e.g. a single clinician may be identified from one of the services to co-ordinate the transition),

Always	
Sometimes	
Never	

Please elaborate on how you carry out the above, and on how you carry out any other aspects of the transition process:

[illegible]

(Please continue on a separate sheet if necessary)

On the next page, please provide us with details of all patients who crossed your transition boundary in 2006 and were or could have been transferred by your service to adult services. The information obtained in this study will be entirely confidential. It will be stored on a computer with each service identified only by a number code. Only the researchers involved in the study will be able to view the information. The mapping report will not identify services and not be circulated. However, it will appear in print at some stage.

Many thanks for your help.

Patient list for January 1st 2006- December 31st 2006

Young people referred (name of the adult service in question)
Young people you might have referred but did not (name of the adult service in question)
Young people you referred (name of the adult service in question) but who were not accepted by adult mental health services

Please continue on a separate sheet if necessary.

Appendix 2: Case note tracking questionnaire for actual referrals

TRACK Stage 2

Case Note Review – Transition from CAMHS to Adult MHS

Actual Referrals

Case no:

Patient name:

Case note reviewer: _____

Date of data collection: _____

This questionnaire should be completed *only if* the young person was successfully transferred to adult services.

When completing:

- in general, tick boxes
- NR=not recorded

SECTION 1: SERVICE / TRANSITION DETAILS**(must be completed prior to completing rest of the form)**

CAMHS Team name and locality: _____

CAMHS Tier: 2 / 2-3 / 4

Team Borough or National/Specialist: _____

Trust: _____

Transitional hierarchy for completion of case note review:Young person referred to AMHS (whether referral accepted or not): Yes ☐ No ☐

- if **yes**, data in Section 2 relates to time that referral was made
- if **no**, data in section 2 relates to time of crossing CAMHS/AMHS boundary (whether young person still being seen by CAMHS or not). In this case, **for this CAMHS**, please specify criteria for crossing **CAMHS/AMHS boundary**:

☐ age (specify: _____),☐ leaving full-time education (specify: secondary school/ 6th form/college), OR☐ other boundary (specify: _____)**Information collected from:**CAMHS notes ☐ CAMHS electronic records ☐ AMHS notes ☐AMHS electronic records ☐ Other ☐ (specify) _____**SECTION 2: DETAILS AT TIME OF REFERRAL TO AMHS/CROSSING TRANSITIONAL BOUNDARY****YOUNG PERSON:**

Date of birth: _____ (date) _____ (month) _____ (year)

Gender: Male / Female

 Address: _____

UR/PID (NHS Patient Identification Number): _____

Ethnic Group [Insert no., see appendix 1]: ____ NR ☐

First Language: English ☐ Other ☐ (please state _____) NR ☐

Second language: English ☐ Other ☐ (please state _____) NR ☐

Age: _____

• **If the young person is under 18:**

- name of identified person with parental responsibility:

address: _____

tel. no.: _____

- A Looked After Child? Yes ☐ No ☐

• **If the young person is over 18 years:**

- Does he/she have an identified carer? Yes ☐ No ☐
- Relationship to young person: Parent ☐ Sibling ☐ Extended family member ☐

Partner (or girlfriend/boyfriend) ☐ Friend ☐ Other ☐ (please state _____)

Young person's living arrangements:

On own ☐ parental home ☐ mother's home ☐ father's home ☐ foster carer's home ☐

shared accommodation (not with family) ☐ in another's home (describe relationship) ☐

Are other agencies involved with the young person?

☐ health (please state _____)

☐ social care (please state _____)

☐ education (please state _____)

☐ voluntary (please state _____)

Is the young person in education?

Full time ☐ Part time ☐ No ☐ NR ☐

If so: School ☐ college ☐ other ☐ (specify: _____)

What is the highest level of education reached to date?

Some School ☐ GCSE ☐ Some college ☐ A-level ☐

Other ☐ (specify: _____) NR ☐

Is the young person currently in employment?

Full time ☐ Part time ☐ No ☐ NR ☐

If so, specify type: _____

FAMILY DETAILS AT TIME OF REFERRAL TO AMHS/CROSSING TRANSITIONAL BOUNDARY

Parents' details:

Married & cohabiting ☐ Cohabiting ☐ Separated ☐ Divorced ☐ NR ☐

If parents separated or divorced or looked after child (specify which or both): _____

Current contact with mother: regular ☐ irregular ☐ none ☐

Current contact with father: regular ☐ irregular ☐ none ☐

Parental Occupation: Father _____ / NR ☐

Mother _____ / NR ☐

Family history of mental health difficulties:

Overall: Yes ☐ No ☐ NR ☐

Mum Yes ☐ No ☐ NR ☐

Dad Yes ☐ No ☐ NR ☐

Siblings Yes ☐ No ☐ NR ☐

Uncles/aunts Yes ☐ No ☐ NR ☐

Grandparents Yes ☐ No ☐ NR ☐

Other family Yes ☐ No ☐ NR ☐

Family members who attend CAMHS

Mother: regularly ☐ sometimes ☐ never ☐

Father: regularly ☐ sometimes ☐ never ☐

One or more siblings: regularly ☐ sometimes ☐ never ☐

Other family member(s):

please specify _____: regularly ☐ sometimes ☐ never ☐

please specify _____: regularly ☐ sometimes ☐ never ☐

please specify _____: regularly ☐ sometimes ☐ never ☐

Has a carer's assessment been offered at any stage?

If so, by whom? CAMHS ☐ Adult MHS ☐ Other ☐ (specify _____)

If so, when? Before transition ☐ at time of transition ☐ after transition ☐

Was it accepted? Yes ☐ No ☐ NR ☐

Was it carried out? Yes ☐ No ☐ NR ☐

SECTION 3: DETAILS OF REFERRAL TO CAMHS FOR THE EPISODE OF CARE RESULTING IN REFERRAL TO AMHS OR CROSSING OF TRANSITIONAL BOUNDARY

Referral: Routine ☐ Urgent ☐

Referred by: General Practitioner ☐ Paediatrician ☐ Health Visitor ☐

School Nurse or School Health Advisor ☐ Other Education-based professional ☐ Social Worker ☐
☐ Self or family referral ☐ Another CAMHS ☐ Other ☐ (specify _____)

Reasons for referral? (tick as many as are relevant)

Emotional (e.g. anxiety, depression, OCD) ☐ Behavioural ☐

Developmental (e.g. autism spectrum disorder, ADHD) ☐ Eating Disorder ☐ Psychosis ☐

Family relationship issues ☐ Crisis or complex psychosocial (e.g. deliberate self harm) ☐

Learning difficulties ☐ Poor academic progress ☐ peer problems ☐

Other ☐ (specify _____)

SECTION 4: DETAILS OF ASSESSMENT AT CAMHS DURING THE EPISODE OF CARE RESULTING IN REFERRAL TO AMHS OR CROSSING OF TRANSITIONAL BOUNDARY

How many weeks between referral and assessment? _____

Assessed by (specify number of each profession in brackets):

Mental Health Nurse () Clinical Psychologist () Psychiatrist ()

Social Worker () Primary Mental Health Worker ()

Family/Systemic Therapist () Psychotherapist (e.g. psychodynamic) ()

Experiential Therapist (e.g. Art, Drama. Specify: _____) ()

Paediatrician () Paediatric Nurse () Other (specify _____) ()

Initial Diagnoses (from correspondence to referrer/case notes):

Clinical diagnoses / key problems: _____

ICD 10 diagnoses: _____ code: _____

DSM 4 code diagnoses: _____ code: _____

Other: _____

Previous contact with this CAMHS / another CAMHS

specify number _____ nil ☐ NR ☐

Age at first referral to any CAMHS _____

Number of other CAMHS attended _____

Age at first referral to this CAMHS _____

Number of previous (not including this referral) referrals to this CAMHS _____

Number of previous referrals to this CAMHS not accepted by service _____

Cumulative length of episodes of care, prior to this episode, at this CAMHS _____

List all known diagnoses / key problems for all previous contact with any CAMHS:

SECTION 5: DETAILS OF SUBSEQUENT CONTACT WITH THIS CAMHS

Interventions delivered (tick as many as relevant)

Medication ☐ Family Therapy ☐ General support or follow up ☐

Individual therapy (Type if noted, e.g. CBT, psychodynamic. _____) ☐

Parenting support (Type if noted, e.g. groups/ parallel or separate sessions with/from individual sessions for child _____) ☐

Experiential Therapy (Type if noted, e.g. Art Therapy: _____) ☐

Consultation / liaison with other agencies ☐

If so: School Education ☐ Social Services ☐ YOT (Youth Offending Service) ☐

Multi-agency ☐ Other (specify _____) ☐

Other (specify: _____) ☐

CAMHS professionals who delivered face-to-face work or consultation:

Total number: _____

Mental Health Nurse () Clinical Psychologist () Psychiatrist ()

Social Worker () Primary Mental Health Worker ()

Family/Systemic Therapist () Psychotherapist (e.g. psychodynamic) ()

Experiential Therapist (e.g. Art, Drama. Specify: _____) ()

Paediatrician () Paediatric Nurse () Other (specify _____) ()

Discipline of CAMHS case manager(s)/key-worker(s): _____

Status: While attending CAMHS, was the young person, at any time:

- A Looked After Child (in Care) / attending Leaving Care services
Yes ☐ No ☐ NR ☐
- Given a Statement of Special Educational Needs: Yes ☐ No ☐ NR ☐
- On the Child Protection Register: Yes ☐ No ☐ NR ☐
 - If yes, specify categories:
physical abuse ☐ emotional abuse ☐ sexual abuse ☐ neglect ☐
- Admitted to hospital for mental health problems: Yes ☐ No ☐ NR ☐
 - ☐ mental health unit
 - ☐ paediatric unit
- Detained under a section of the Mental Health Act 1983
 - Yes ☐ No ☐ NR ☐

- If yes; Section 2 ☐ Section 3 ☐ other ☐ (specify_____)
- Involved with YOT Yes ☐ No ☐ NR ☐
- Refugee or asylum seeker Yes ☐ No ☐ NR ☐

SECTION 6: DETAILS AT TIME OF REFERRAL TO AMHS / CROSSING TRANSITIONAL BOUNDARY

Number of weeks between assessment at CAMHS and referral to AMHS/ crossing transitional boundary: _____

CLINICAL DETAILS

Clinicians involved (specify number of each profession in brackets:

Mental Health Nurse () Clinical Psychologist () Psychiatrist ()

Social Worker () Primary Mental Health Worker ()

Family/Systemic Therapist () Psychotherapist (e.g. psychodynamic) ()

Experiential Therapist (e.g. Art, Drama. Specify:_____) ()

Paediatrician () Paediatric Nurse () Other (specify _____) ()

Discipline of CAMHS case manager(s)/key-worker(s):_____

Diagnoses / Impression (from correspondence/case notes):

Clinical diagnoses / key problems: _____

ICD 10 diagnoses: _____ code: _____

DSM 4 code diagnoses: _____ code: _____

Other: _____

Interventions being delivered (tick as many as relevant)

Medication ☐ Family Therapy ☐ General support or follow up ☐

Individual therapy (Type if noted, e.g. CBT, psychodynamic._____) ☐

Parenting support (Type if noted, e.g. groups/ parallel or separate sessions with/from individual sessions for child_____) ☐

Experiential Therapy (Type if noted, e.g. Art Therapy: _____) ☐

Consultation / liaison with other agencies ☐

If so: Early Intervention in Psychosis Team (EIT) ☐ other AMHS ☐ School/Education ☐

Social Services ☐ Multi-agency ☐ other ☐ (specify _____)

Other (specify: _____)

Status:

- A Looked After Child (in Care) / attending Leaving Care services
Yes ☐ No ☐ NR ☐
- Has a Statement of Special Educational Needs: Yes ☐ No ☐ NR ☐
- On the Child Protection Register: Yes ☐ No ☐ NR ☐
 - If yes, specify categories:
physical abuse ☐ emotional abuse ☐ sexual abuse ☐ neglect ☐
- In a hospital for mental health problems: Yes ☐ No ☐ NR ☐
 - ☐ mental health unit
 - ☐ paediatric unit
- Detained under a section of the Mental Health Act 1983
 - Yes ☐ No ☐ NR ☐
 - If yes; Section 2 ☐ Section 3 ☐ other ☐ (specify _____)
- Care Programme Approach (CPA)
 - Yes ☐ No ☐ NR ☐
 - Standard ☐ Enhanced ☐
- Involved with YOT Yes ☐ No ☐ NR ☐
- Refugee or asylum seeker Yes ☐ No ☐ NR ☐

REFERRAL DETAILS

Method of *successful* referral: (tick as many as are relevant; this refers to the ultimately successful referral to adult services. Any initial unsuccessful referrals will be recorded later)

Letter ☐ telephone ☐ electronic ☐ other ☐ (specify _____)

If letter, copied to: GP ☐ young person ☐ Parent(s)/carer(s) ☐ Other ☐ (specify _____)

Clinicians involved in *successful* referral:

Discipline of clinician making any referral to AMHS: _____

To whom the referral was sent: Discipline of clinician, if specified _____

Specific AMHS:

Reason for referral: Presentation (tick as many as indicated)

- ☐ on going mental health problems/disorders requiring specialist treatment: specify medication and/or psychological treatment and/ or monitoring

- ☐ new episode of the mental health problem(s)/disorder(s) for which the young person was already seen by CAMHS
- ☐ new episode of a different mental health problem(s)/disorder(s) in a young person who was already seen by CAMHS for a different problem/disorder
- ☐ new episode of mental health problem(s)/disorder(s) in a young person newly referred to and assessed by CAMHS
- ☐ new episode of mental health problem(s)/disorder(s) in a young person newly referred to but not assessed by CAMHS
- ☐ Management of risk (specify: self-harm or suicide ☐ harm to others ☐
self-neglect ☐ vulnerability to abuse ☐)
- ☐ other (specify: _____)

Detail in referral: (circle as many as indicated)

- o Diagnoses or presentation: included ☐ not included ☐
- o current treatment: included ☐ not included ☐
- o past mental health history: included ☐ not included ☐
- o past medical history: included ☐ not included ☐
- o family history: included ☐ not included ☐
- o family mental health history: included ☐ not included ☐
- o current household: included ☐ not included ☐
- o current status: included ☐ not included ☐

Successful Referral to:

Type of AMHS: CMHT ☐ consultant psychiatrist ☐ Psychology Team ☐

adult inpatient unit ☐ Early Intervention I Psychosis Team ☐

Eating Disorders Service ☐ Learning Disability Service ☐ Forensic Service ☐

Adult psychotherapy Service ☐ Other ☐ (specify _____)

Reason for choice of service: (tick as many as appropriate):

local service ☐ type of assessment required ☐ type of intervention required ☐

type of disorder or condition ☐ severity of disorder or condition ☐ patient preference ☐

parent or carer preference ☐ other ☐ (specify _____)

Other unavailable services that would have been referred to: _____

Number of weeks between referral being made and any response from AMHS: _____

Number of weeks between referral being made and decision from AMHS: _____

Decision about referral made by AMHS:

- accepted and allocated ☐ accepted to waiting list ☐
- following discussion with CAMHS ☐ without discussion ☐

If not ultimately accepted by any CAMHS, fill in potential referral questionnaire instead of this one.

Details of any unsuccessful referrals:

Were any unsuccessful attempts at referring to AMHS made prior / concurrently to this referral?

Yes ☐ No ☐

If yes:

- What was method of unsuccessful referral (tick as many as are relevant)?

Letter ☐ telephone ☐ electronic ☐ other ☐ (specify _____)

If letter, copied to: GP ☐ young person ☐ Parent(s)/carer(s) ☐ Other ☐ (_____)

- What discipline was the clinician who made the unsuccessful referral to AMHS?

- To whom the unsuccessful referral was sent:
 Discipline of clinician, if specified _____
 Specific AMHS: _____
- Type of AMHS: CMHT ☐ consultant psychiatrist ☐ Psychology Team ☐
 adult inpatient unit ☐ Early Intervention I Psychosis Team ☐
 Eating Disorders Service ☐ Learning Disability Service ☐ Forensic Service ☐
 Adult psychotherapy Service ☐ Other ☐ (specify _____)
- Reason for choice of service: (tick as many as appropriate):
 Local service ☐ type of assessment required ☐ type of intervention required ☐
 type of disorder or condition ☐ severity of disorder or condition ☐
 patient preference ☐ parent or carer preference ☐ other ☐ (specify _____)
- Non-acceptance of referral communicated: to CAMHS referrer ☐ to young person ☐
 to parent(s)/carer(s) ☐ to General Practitioner ☐
- Reason: does not meet referral criteria ☐
 no relevant service available (specify what service: _____) ☐
 no relevant expertise (specify in what: _____) ☐
 No reason ☐ other reason (specify _____) ☐
- Alternative sources of help suggested: no ☐ yes ☐ (specify _____)

TRANSITION PROCESS

Preparation of family:

Transfer of care mentioned to young person: Yes (date: _____) ☐ No ☐ NR ☐

Transfer of care mentioned to parent(s)/carer(s): Yes (date: _____) ☐ No ☐ NR ☐

Young person's consent for referral to AMHS sought:

documented clearly ☐ inferred ☐ not recorded ☐

Reason for transfer to AMHS communicated to young person:

documented clearly ☐ inferred ☐ not recorded ☐

Discussion about the ending of the therapeutic relationship(s):

documented clearly ☐ inferred ☐ not recorded ☐

Preparation for professionals

Transition planning meeting between CAMHS and AMHS (number):

(___) offered by CAMHS but not taken up by AMHS

(___) offered but not arranged

(___) offered and arranged

(___) discussion between professionals alongside joint appointment with young person

(___) discussion between professionals alongside joint appointment with parent(s)/carer(s)

(___) discussion between professionals alongside joint appointment with young person and parent(s)/carer(s)

AMHS staff involved in transition planning meeting (identify* professionals the young person will see, if they are involved):

_____ Involved? Yes ☐ No ☐

_____ Involved? Yes ☐ No ☐

CAMHS staff involved in transition planning meeting (identify* professionals the young person has been seeing, if they are involved):

_____ Involved? Yes ☐ No ☐

_____ Involved? Yes ☐ No ☐

Contents (tick as many as necessary): timeframe ☐ transition boundary ☐

reasons for suggested referral to AMHS ☐ information about AMHS ☐

what will be initially offered by AMHS ☐ who will initially see the young person ☐

change from family-oriented service to individual-oriented service ☐ Issues of consent ☐

concerns of young person ☐ concerns of parent/carers ☐ preferences of young person ☐

preferences of parent(s)/carer(s) ☐ Other points/concerns raised (specify): _____

Additional telephone contact: Yes ☐ No ☐ NR ☐

Reason: _____

Between: _____

Additional Email contact: Yes ☐ No ☐ NR ☐

Reason: _____

Between: _____

Additional letter contact: Yes ☐ No ☐ NR ☐

Reason: _____

Between: _____

Other (details): _____

Between: _____

Duration of joint transition planning (up to transfer of care): Number of weeks: _____

Handover of care

- Successive appointments with CAMHS then AMHS: yes ☐ no ☐
- Joint appointment(s) with CAMHS/AMHS: offered by CAMHS but not taken up by AMHS ☐
offered but not arranged ☐ offered and arranged ☐
- If not offered, any reason documented? _____
- If arranged:
 - attended by (list):
 - ☐ Young person and other family or friends: _____

 - ☐ Professionals from AMHS _____

 - ☐ Professionals from CAMHS _____

 - Took place at: CAMHS ☐ AMHS ☐ other ☐ (specify: _____)
 - Took place at: last CAMHS appointment ☐ first AMHS appointment ☐ neither ☐

Any other steps taken to prepare the family for the process of transition?

Young person: _____

parent(s)/carer(s): _____

Period of parallel care between CAMHS and AMHS?

Duration (weeks): _____ Number of sessions: _____

Reason: _____

Documentation transferred to AMHS (tick as many as necessary)

Referral letter ☐ summary of CAMHS contact ☐ some CAMHS notes ☐ all CAMHS notes ☐
contemporary risk assessment ☐ Care Programme Approach documents (if on CPA) ☐

Other ☐ (specify _____)

SECTION 7: AMHS CONTACT DETAILS

CLINICAL DETAILS

First seen by: (specify number of each profession in brackets):

Mental Health Nurse () Clinical Psychologist () Psychiatrist ()

Social Worker () Primary Mental Health Worker () Family/Systemic Therapist ()

Psychotherapist (e.g. Psychodynamic) ()

Experiential Therapist (e.g. Art, Drama. Specify: _____) ()

Occupational Therapist () other (specify _____) ()

Subsequently seen by: (specify number of each profession in brackets):

Mental Health Nurse () Clinical Psychologist () Psychiatrist ()

Social Worker () Primary Mental Health Worker () Family/Systemic Therapist ()

Psychotherapist (e.g. Psychodynamic) ()

Experiential Therapist (e.g. Art, Drama. Specify: _____) ()

Occupational Therapist () other (specify _____) ()

Discipline of case manager(s)/key-worker(s): _____

First appointment offered by AMHS

Number of weeks between referral by CAMHS and first appointment **offered** by AMHS: _____

Joint meeting with CAMHS: yes ☐ no ☐

Appointment withdrawn and young person discharged because of:

disengagement with CAMHS ☐ non-response to AMHS attempts to arrange appointment ☐

Attended: by young person ☐ young person and parent(s)/carer(s) ☐

parent(s)/carer(s) only ☐ DNA ☐

If DNA, what was the outcome? Discharged ☐ further appointment ☐

Diagnoses / Impression following initial assessment

Clinical diagnoses / key problems: _____

ICD 10 diagnoses: _____ code: _____

DSM 4 code diagnoses: _____ code: _____

Outcome of initial assessment:

discharged ☐ on-going clinical management ☐ DNA: Further appointment ☐

Second appointment

- Number of weeks after first _____ No second appointment ☐
- Type: General follow-up ☐ specific intervention ☐ (specify _____)
- Attended: by young person ☐ young person and parent(s)/carer(s) ☐
- parent(s)/carer(s) only ☐ DNA ☐
- If DNA, outcome: Discharged ☐ further appointment ☐

Interventions offered overall (tick as many as relevant, and whether refused or accepted by young person)

Inpatient admission: Number _____

For each: refused / accepted _____

duration

status (voluntary / under MHA [specify section]) _____

Day facility attendance: specify _____ refused ☐ accepted ☐

Medication: specify _____ refused ☐ accepted ☐

Family Therapy: Behavioural ☐ Systemic ☐ other ☐ refused ☐ accepted ☐

General support or follow up _____ refused ☐ accepted ☐

Individual therapy: Type if noted _____ refused ☐ accepted ☐

Carer support: _____ refused ☐ accepted ☐

Type if noted, e.g. groups/ parallel or separate sessions with/from individual sessions for young person) _____

Experiential Therapy: Type: _____ refused ☐ accepted ☐

Consultation with other agencies: specify _____ refused ☐ accepted ☐

Referral

To other AMHS: specify _____ refused ☐ accepted ☐

To other voluntary or statutory agencies: specify _____ refused ☐ accepted ☐

Other: specify: _____ refused ☐ accepted ☐

Status (at any time in contact with AMHS):

- A Looked After Child (in Care) / attending Leaving Care services
Yes ☐ No ☐ NR ☐
- Has a Statement of Special Educational Needs: Yes ☐ No ☐ NR ☐
- On the Child Protection Register: Yes ☐ No ☐ NR ☐
 - If yes, specify categories:
physical abuse ☐ emotional abuse ☐ sexual abuse ☐ neglect ☐
- In a hospital for mental health problems: Yes ☐ No ☐ NR ☐
 - ☐ mental health unit
 - ☐ paediatric unit
- Detained under a section of the Mental Health Act 1983
 - Yes ☐ No ☐ NR ☐
 - If yes; Section 2 ☐ Section 3 ☐ other ☐ (specify _____)

- Care Programme Approach (CPA)
 - Yes ☐ No ☐ NR ☐
 - Standard ☐ Enhanced ☐
- Involved with YOT Yes ☐ No ☐ NR ☐
- Refugee or asylum seeker Yes ☐ No ☐ NR ☐

Attendance at AMHS

Discharged ☐ open but lost to follow up ☐ open but infrequent attendance ☐

open and regular attendance ☐

If discharged at any point by AMHS

- reason: presenting problem resolved altogether ☐
 - presenting problem resolved somewhat ☐ does not meet referral criteria ☐
 - no relevant service available (specify what service: _____) ☐
 - no relevant expertise (specify in what: _____) ☐ No reason ☐ DNA ☐
 - other reason ☐ (specify _____)
- Alternative sources of help suggested: no ☐ yes ☐ (specify _____)
- Discharge communicated: to CAMHS referrer ☐ to General Practitioner ☐
 - to young person ☐ to parent(s)/carer(s) ☐

If discharged and CAMHS informed, what was CAMHS response? (tick as many as relevant)

- ☐ continued efforts to refer to AMHS:
 - ☐ re-referral to another AMHS
 - ☐ telephone consultation with AMHS (n=)
 - ☐ face to face consultation with AMHS (n=)
- ☐ discharged to primary care / other health service (specify:)
- ☐ further appointment considering options then discharged to primary care
- ☐ referral to other agencies (voluntary and statutory): list _____
- ☐ On-going input from CAMHS

If ongoing input: Number of sessions _____ Duration of contact (weeks) _____

Subsequently closed? Yes ☐ No ☐

In any case:

How many appointments offered in the first three months? _____

How many appointments attended (%)? _____

How long has there been between the first appointment and now / discharge in weeks? _____

If poor attendance (two successive appointments missed at any time), what efforts were made to engage the young person?

- Letters: Yes (n=) ☐ No ☐ NR ☐
- Phonecalls: Yes (n=) ☐ No ☐ NR ☐
- Other: specify _____

If poor attendance, what efforts were made to contact the parent(s)/carer(s)?

- Letters: Yes (n=) ☐ No ☐ NR ☐
- Phonecalls: Yes (n=) ☐ No ☐ NR ☐
- Other: specify _____

If poor attendance, any contact with:

- ☐ CAMHS? Specify _____
- ☐ General Practitioner? Specify _____

SECTION 8: DETAILS USEFUL FOR PARTICIPATION IN STAGE 4

Last known address: _____

Phone number: _____

Last known GP and contact details: _____

Details of any current case manager/key worker:

Name: _____ Role: _____

Service contact details: _____

Any general comments on the nature of the transition (positive / negative etc):

Appendix 1: Ethnicity Classification (from Census 2001 Ethnicity Classification System)

1. White British	7. Other Mixed	13. African
2. White Irish	Background	14. Other Black
3. Other White	8. Indian	Background
Background	9. Pakistani	15. Chinese
4. Mixed White and	10. Bangladeshi	16. Other ethnic group
Black Caribbean	11. Other Asian	(please state)
5. Mixed White and	Background	
Black African	12. Caribbean	
6. Mixed White and		
Asian		

Appendix 3: Case note tracking questionnaire for potential referrals

TRACK Stage 2

Case Note Review – Transition from CAMHS to Adult MHS

Potential Referrals

Case no: _____

Patient name: _____

Case note reviewer: _____

Date of data collection: _____

This questionnaire should be completed if AMHS did not accept the referral, or if the young person crossed the transition boundary but was not subsequently referred to AMHS

When completing:

- in general, tick boxes
- NR=not recorded

Potential Referral Questionnaire completed because:

- a) AMHS did not accept referral ☐
- b) young person crossed transition boundary but was not referred to AMHS ☐
- c) A referral has been made but AMHS have not yet made their final decision ☐

If c) how many weeks between referral to adult services and now? _____

SECTION 1: SERVICE / TRANSITION DETAILS

CAMHS Team name and locality: _____

CAMHS Tier: 2 / 2-3 / 4

Team Borough or National/Specialist: _____

Trust: _____

Transitional hierarchy for completion of case note review:

Young person referred to AMHS (whether referral accepted or not): Yes ☐ No ☐

- o if **yes**, data in Section 2 relates to time that referral was made
- o if **no**, data in section 2 relates to time of crossing CAMHS/AMHS boundary (whether young person still being seen by CAMHS or not). In this case, **for this CAMHS**, please specify criteria for crossing **CAMHS/AMHS boundary**:

☐ age (specify: _____),

☐ leaving full-time education (specify: secondary school/ 6th form/college), OR

☐ other boundary (specify: _____)

Information collected from:

CAMHS notes ☐ CAMHS electronic records ☐ AMHS notes ☐

AMHS electronic records ☐ Other ☐ (specify) _____

SECTION 2: DETAILS AT TIME OF REFERRAL TO AMHS/CROSSING TRANSITIONAL BOUNDARY**YOUNG PERSON:**

Date of birth: _____ (date) _____ (month) _____ (year)

Gender: Male / Female

Address: _____

UR/PID (NHS Patient Identification Number): _____

Ethnic Group [Insert no., see appendix 1]: _____ NR ☐

First Language: English ☐ Other ☐ (please state _____) NR ☐

Second language: English ☐ Other ☐ (please state _____) NR ☐

Age: _____

• **If the young person is under 18:**

- name of identified person with parental responsibility:

address: _____

tel. no.: _____

- A Looked After Child? Yes ☐ No ☐

• **If the young person is over 18 years:**

- Does he/she have an identified carer? Yes ☐ No ☐

- Relationship to young person: Parent ☐ Sibling ☐ Extended family member ☐

Partner (or girlfriend/boyfriend) ☐ Friend ☐ Other ☐ (please state _____)

Young person's living arrangements:

On own ☐ parental home ☐ mother's home ☐ father's home ☐ foster carer's home ☐
 shared accommodation (not with family) ☐ in another's home (describe relationship) ☐

Are other agencies involved with the young person?

☐ health (please state _____)

☐ social care (please state _____)

☐ education (please state _____)

☐ voluntary (please state _____)

Is the young person in education?

Full time ☐ Part time ☐ No ☐ NR ☐

If so: School ☐ college ☐ other ☐ (specify:_____)

What is the highest level of education reached to date?

Some School ☐ GCSE ☐ Some college ☐ A-level ☐

Other ☐ (specify:_____) NR ☐

Is the young person currently in employment?

Full time ☐ Part time ☐ No ☐ NR ☐

If so, specify type: _____

FAMILY DETAILS AT TIME OF REFERRAL TO AMHS/CROSSING TRANSITIONAL BOUNDARY

Parents' details:

Married & cohabiting ☐ Cohabiting ☐ Separated ☐ Divorced ☐ NR ☐

If parents separated or divorced or looked after child (specify which or both): _____

Current contact with mother: regular ☐ irregular ☐ none ☐

Current contact with father: regular ☐ irregular ☐ none ☐

Parental Occupation: Father _____ / NR ☐

Mother _____ / NR ☐

Family history of mental health difficulties:

Overall: Yes ☐ No ☐ NR ☐

Mum Yes ☐ No ☐ NR ☐

Dad Yes ☐ No ☐ NR ☐

Siblings Yes ☐ No ☐ NR ☐

Uncles/aunts Yes ☐ No ☐ NR ☐

Grandparents Yes ☐ No ☐ NR ☐

Other family Yes ☐ No ☐ NR ☐

Family members who attend CAMHS

Mother: regularly ☐ sometimes ☐ never ☐

Father: regularly ☐ sometimes ☐ never ☐

One or more siblings: regularly ☐ sometimes ☐ never ☐

Other family member(s):

please specify _____: regularly ☐ sometimes ☐ never ☐

please specify _____: regularly ☐ sometimes ☐ never ☐

please specify _____: regularly ☐ sometimes ☐ never ☐

Has a carer's assessment been offered at any stage?

If so, by whom? CAMHS ☐ Adult MHS ☐ Other ☐ (specify _____)

If so, when? Before transition ☐ at time of transition ☐ after transition ☐

Was it accepted? Yes ☐ No ☐ NR ☐

Was it carried out? Yes ☐ No ☐ NR ☐

SECTION 3: DETAILS OF REFERRAL TO CAMHS FOR THE EPISODE OF CARE RESULTING IN REFERRAL TO AMHS OR CROSSING OF TRANSITIONAL BOUNDARY

Referral: Routine ☐ Urgent ☐

Referred by: General Practitioner ☐ Paediatrician ☐ Health Visitor ☐

School Nurse or School Health Advisor ☐ Other Education-based professional ☐ Social Worker
☐ Self or family referral ☐ Another CAMHS ☐ Other ☐ (specify _____)

Reasons for referral? (tick as many as are relevant)Emotional (e.g. anxiety, depression, OCD) ☐ Behavioural ☐Developmental (e.g. autism spectrum disorder, ADHD) ☐ Eating Disorder ☐ Psychosis ☐Family relationship issues ☐ Crisis or complex psychosocial (e.g. deliberate self harm) ☐Learning difficulties ☐ Poor academic progress ☐ peer problems ☐Other ☐ (specify _____)**SECTION 4: DETAILS OF ASSESSMENT AT CAMHS DURING THE EPISODE OF CARE
RESULTING IN REFERRAL TO AMHS OR CROSSING OF TRANSITIONAL BOUNDARY**

How many weeks between referral and assessment? _____

Assessed by (specify number of each profession in brackets):

Mental Health Nurse () Clinical Psychologist () Psychiatrist ()

Social Worker () Primary Mental Health Worker ()

Family/Systemic Therapist () Psychotherapist (e.g. psychodynamic) ()

Experiential Therapist (e.g. Art, Drama. Specify: _____) ()

Paediatrician () Paediatric Nurse () Other (specify _____) ()

Initial Diagnoses (from correspondence to referrer/case notes):

Clinical diagnoses / key problems: _____

ICD 10 diagnoses: _____ code: _____

DSM 4 code diagnoses: _____ code: _____

Other: _____

Previous contact with this CAMHS / another CAMHSspecify number _____ nil ☐ NR ☐

Age at first referral to any CAMHS _____

Number of other CAMHS attended _____

Age at first referral to this CAMHS _____

Number of previous (not including this referral) referrals to this CAMHS _____

Number of previous referrals to this CAMHS not accepted by service _____

Cumulative length of episodes of care, prior to this episode, at this CAMHS _____

List all known diagnoses / key problems for all previous contact with any CAMHS:

SECTION 5: DETAILS OF SUBSEQUENT CONTACT WITH THIS CAMHS

Interventions delivered (tick as many as relevant)

Medication ☐ Family Therapy ☐ General support or follow up ☐

Individual therapy (Type if noted, e.g. CBT, psychodynamic. _____) ☐

Parenting support (Type if noted, e.g. groups/ parallel or separate sessions with/from individual sessions for child _____) ☐

Experiential Therapy (Type if noted, e.g. Art Therapy: _____) ☐

Consultation / liaison with other agencies ☐

If so: School Education ☐ Social Services ☐ YOT (Youth Offending Service) ☐

Multi-agency ☐ Other (specify _____) ☐

Other (specify: _____) ☐

CAMHS professionals who delivered face-to-face work or consultation:

Total number: _____

Mental Health Nurse () Clinical Psychologist () Psychiatrist ()

Social Worker () Primary Mental Health Worker ()

Family/Systemic Therapist () Psychotherapist (e.g. psychodynamic) ()

Experiential Therapist (e.g. Art, Drama. Specify: _____) ()

Paediatrician () Paediatric Nurse () Other (specify _____) ()

Discipline of CAMHS case manager(s)/key-worker(s): _____

Status: While attending CAMHS, was the young person, at any time:

- A Looked After Child (in Care) / attending Leaving Care services
Yes ☐ No ☐ NR ☐
- Given a Statement of Special Educational Needs: Yes ☐ No ☐ NR ☐
- On the Child Protection Register: Yes ☐ No ☐ NR ☐
 - If yes, specify categories:
physical abuse ☐ emotional abuse ☐ sexual abuse ☐ neglect ☐
- Admitted to hospital for mental health problems: Yes ☐ No ☐ NR ☐
 - ☐ mental health unit
 - ☐ paediatric unit
- Detained under a section of the Mental Health Act 1983
 - Yes ☐ No ☐ NR ☐
 - If yes; Section 2 ☐ Section 3 ☐ other ☐ (specify _____)
- Involved with YOT Yes ☐ No ☐ NR ☐
- Refugee or asylum seeker Yes ☐ No ☐ NR ☐

SECTION 6: DETAILS AT TIME OF REFERRAL TO AMHS / CROSSING TRANSITIONAL BOUNDARY

Number of weeks between assessment at CAMHS and referral to AMHS/ crossing transitional boundary: _____

CLINICAL DETAILS

Clinicians involved (specify number of each profession in brackets):

Mental Health Nurse () Clinical Psychologist () Psychiatrist ()

Social Worker () Primary Mental Health Worker ()

Family/Systemic Therapist () Psychotherapist (e.g. psychodynamic) ()

Experiential Therapist (e.g. Art, Drama. Specify: _____) ()

Paediatrician () Paediatric Nurse () Other (specify _____) ()

Discipline of CAMHS case manager(s)/key-worker(s): _____

Diagnoses / Impression (from correspondence/case notes):

Clinical diagnoses / key problems: _____

ICD 10 diagnoses: _____ code: _____

DSM 4 code diagnoses: _____ code: _____

Other: _____

Interventions being delivered (tick as many as relevant)

Medication ☐ Family Therapy ☐ General support or follow up ☐

Individual therapy (Type if noted, e.g. CBT, psychodynamic. _____) ☐

Parenting support (Type if noted, e.g. groups/ parallel or separate sessions with/from individual sessions for child _____) ☐

Experiential Therapy (Type if noted, e.g. Art Therapy: _____) ☐

Consultation / liaison with other agencies ☐

If so: Early Intervention in Psychosis Team (EIT) ☐ other AMHS ☐ School Education ☐

Social Services ☐ Multi-agency ☐ other ☐ (specify _____)

Other (specify: _____)

Status:

- A Looked After Child (in Care) / attending Leaving Care services
Yes ☐ No ☐ NR ☐
- Has a Statement of Special Educational Needs: Yes ☐ No ☐ NR ☐
- On the Child Protection Register: Yes ☐ No ☐ NR ☐
 - If yes, specify categories:
physical abuse ☐ emotional abuse ☐ sexual abuse ☐ neglect ☐
- In a hospital for mental health problems: Yes ☐ No ☐ NR ☐
 - ☐ mental health unit
 - ☐ paediatric unit
- Detained under a section of the Mental Health Act 1983
 - Yes ☐ No ☐ NR ☐
 - If yes; Section 2 ☐ Section 3 ☐ other ☐ (specify _____)
- Care Programme Approach (CPA)
 - Yes ☐ No ☐ NR ☐
 - Standard ☐ Enhanced ☐

- Involved with YOT Yes ☐ No ☐ NR ☐
- Refugee or asylum seeker Yes ☐ No ☐ NR ☐

REFERRAL DETAILS.

NB when entering this information in database, put in unsuccessful referrals section

Method: (tick as many as are relevant)

Letter ☐ telephone ☐ electronic ☐ other ☐ (specify _____)

If letter, copied to: GP ☐ young person ☐ Parent(s)/carer(s) ☐ Other ☐ (specify _____)

Clinicians:

Discipline of clinician making any referral to AMHS: _____

To whom the referral was sent:

Discipline of clinician, if specified _____

Specific AMHS: _____

Reason for referral: Presentation (tick as many as indicated)

- ☐ on going mental health problems/disorders requiring specialist treatment: specify medication and/or psychological treatment and/ or monitoring _____
- ☐ new episode of the mental health problem(s)/disorder(s) for which the young person was already seen by CAMHS
- ☐ new episode of a different mental health problem(s)/disorder(s) in a young person who was already seen by CAMHS for a different problem/disorder
- ☐ new episode of mental health problem(s)/disorder(s) in a young person newly referred to and assessed by CAMHS
- ☐ new episode of mental health problem(s)/disorder(s) in a young person newly referred to but not assessed by CAMHS
- ☐ Management of risk (specify: self-harm or suicide ☐ harm to others ☐
self-neglect ☐ vulnerability to abuse ☐
- ☐ other (specify: _____)

Detail in referral: (circle as many as indicated)

- Diagnoses or presentation: included ☐ not included ☐
- current treatment: included ☐ not included ☐
- past mental health history: included ☐ not included ☐
- past medical history: included ☐ not included ☐
- family history: included ☐ not included ☐
- family mental health history: included ☐ not included ☐
- current household: included ☐ not included ☐
- current status: included ☐ not included ☐

Referral to:

Type of AMHS: CMHT ☐ consultant psychiatrist ☐ Psychology Team ☐

adult inpatient unit ☐ Early Intervention I Psychosis Team ☐

Eating Disorders Service ☐ Learning Disability Service ☐ Forensic Service ☐

Adult psychotherapy Service ☐ Other ☐ (specify _____)

Reason for choice of service: (tick as many as appropriate):

local service ☐ type of assessment required ☐ type of intervention required ☐

type of disorder or condition ☐ severity of disorder or condition ☐ patient preference ☐

parent or carer preference ☐ other ☐ (specify _____)

Other unavailable services that would have been referred to: _____

Number of weeks between referral being made and any AMHS response: _____

Number of weeks between referral being made and decision from AMHS: _____

Decision about referral made by AMHS: not accepted ☐ not referred ☐ pending ☐

If pending: please record all details of contact with adult services to date. E.g. how long since referral, nature of all contact between CAMHS and AMHS (method, date, subject), the reason for the delay, any joint working between CAMHS and AMHS to date etc.

If not accepted by AMHS:

AMHS response (tick as many as relevant):

- Non-acceptance of referral communicated: to CAMHS referrer ☐ to young person ☐
to parent(s)/carer(s) ☐ to General Practitioner ☐
- Reason: does not meet referral criteria ☐
no relevant service available (specify what service: _____) ☐
no relevant expertise (specify in what: _____) ☐
No reason ☐ other reason (specify _____) ☐
- Alternative sources of help suggested: no ☐ yes ☐ (specify _____)

CAMHS response: (tick as many as relevant)

- ☐ continued efforts to refer to AMHS:
 - ☐ re-referral to another AMHS
 - ☐ telephone consultation with AMHS (n=)
 - ☐ face to face consultation with AMHS (n=)
 - ☐ other (specify _____)
 - ☐ Additional comments: _____
- ☐ discharged to primary care / other health service (specify: _____)
 - if yes, failure of transfer to AMH communicated? yes ☐ no ☐
- ☐ further appointment considering options then discharged to primary care
- ☐ referral to other agencies (voluntary and statutory): list _____
- ☐ On-going input from CAMHS

If ongoing input:

Number of sessions _____

Duration of contact (weeks) _____

Subsequently closed? Yes ☐ No ☐Alternative sources of help suggested by AMHS: no ☐ yes ☐ (specify _____)

Section 7: CAMHS contact details subsequent to *AMHS not accepting referral of young person or young person crossing transition boundary in absence of a referral to AMHS

Number of weeks between now and *: _____

If no referral made to AMHS (tick as many as necessary)

Reason:

- ☐ continuing presentation that meets CAMHS referral criteria but known not to meet AMHS referral criteria
- ☐ need for ongoing specialist mental health care but clinician's perception is that AMHS do not accept referrals for this reason
Specify care required: _____
- ☐ need for ongoing specialist mental health care but clinician's attempts to refer for similar reasons have met with AMHS refusing referral
Specify care required: _____
- ☐ need for ongoing specialist mental health care but clinician's perception is that AMHS do not have the relevant service / expertise / interventions (e.g. family based interventions)
Specify service/expertise/interventions required: _____
- ☐ referral refused by young person
- ☐ referral refused by parent(s)/carer(s)
- ☐ Plan to refer to adult services in the future
- ☐ other:
specify _____

Current age of young person: _____

Outcome:

- ☐ Ongoing care with CAMHS

Number of sessions _____ Duration of contact (weeks) _____

Subsequently closed? Yes ☐ No ☐

If still open, pending referral decision from AMHS? Yes ☐ No ☐

- ☐ Discharged to GP

- ☐ Discharged to Other Service: specify type _____
- ☐ Disengaged
- ☐ Lost to follow up
- ☐ Other: specify

SECTION 8: DETAILS USEFUL FOR PARTICIPATION IN STAGE 4

Last known address: _____

Phone number: _____

Last known GP and contact details: _____

Details of any current case manager/key worker:

Name: _____ Role: _____

Service contact details: _____

Any general comments on the nature of the transition (positive / negative etc):

Appendix 1: Ethnicity Classification (from Census 2001 Ethnicity Classification System)

1. White British	7. Other Mixed Background	13. African
2. White Irish	8. Indian	14. Other Black Background
3. Other White Background	9. Pakistani	15. Chinese
4. Mixed White and Black Caribbean	10. Bangladeshi	16. Other ethnic group (please state)
5. Mixed White and Black African	11. Other Asian Background	
6. Mixed White and Asian	12. Caribbean	

Appendix 4: Stage 3 interview schedule

TRACK

Telephone interview topic guide for staff and managers involved in providing Child and Adolescent Mental Health Services and Adult Mental Health Services

Introduction to TRACK and interview

Thanks for taking part and returning consent form.

Permission to record the interview.

Arrangements for respondent validation of transcripts.

Arrangements for contacting researchers. (Information sheet)

Section 1: Achieving Successful Transition from CAMHS to Adult Mental Health Services

What is the current process for ensuring successful transition from CAMHS to Adult Mental Health Services?

- What is your role in the process? Beginning and ending of role boundary?
- What is the cut-off age or criteria for end of CAMHS and starting age or criteria for take up of adult mental health services in the Trust?
- What services are available to service users/carers during transition? Range of services (including dual diagnosis). Geographical boundaries? Links to voluntary organisations?
- How do the range and availability of services meet user/carer needs?
- Availability of policies and guidelines to staff to inform the process of transition?

How is the service currently organised to achieve successful transition?

- Organisational structures? Management systems?
- Team meetings between CAMHS and Adult Services? Collaborative decision making? Communication of decisions to support transition?
- Arrangements and mechanisms for following up with service users/carers or teams where transition has not occurred or there are problems? How effective are these?
- Resources to support transition? Human resources in teams? Shortages? Use of temporary staff? Access to information and computer equipment?
- What are the greatest challenges to achieving successful transition in the way services are currently organised?

Section 2: Preparing and engaging service users for and in transitional arrangements

How are individual users/carers prepared for and engaged in transitional arrangements?

- How are they involved in decisions about meeting their needs?

- Are there any areas where this might be improved?
- Examples where transition has worked well and why.
- Examples where transition has worked less well and why.

Section 3: Barriers and facilitators to achieving successful transition?

What are the barriers to achieving successful transition?

- Most common three?
 - How to reduce/overcome these?
 - Why do you think these barriers exist?
 - What would help you to overcome them?
-

What are the facilitators (success factors) in achieving successful transition?

- Most common?
 - How to promote/sustain these?
 - Availability to you?
-

Section 4: Inter-agency Working

How do you manage/promote interagency working during transition?

- Priorities in achieving this?
 - Approaches to decision making?

 - **How does this impact on achieving transition?**
 - Please give examples based on your experience.
-

Thank you for taking part in this interview.

Appendix 5: Stage 4 interview schedule for service users

Topic List: Interview Schedules for Service Users

Introduction

Thank you for agreeing to be interviewed today. My name is _____ and I am a researcher based at _____. We are doing a study looking at what happens when a person who is attending a child and adolescent mental health clinic, has their care transferred to an adult mental health service.

As you have moved from one service to another in the past two years we would like to talk to you today about your experiences of mental health services and the time when you stopped going to Child and Adolescent Mental Health Services. This will help us to develop ideas on how to improve services, especially for people who may have to move from one service to another in the future and their carers.

Schedule for service users

- I would like to remind you that all that you tell me will remain confidential. The only situation where this would not apply is if you told me something that made me concerned that there was a risk of serious harm to either yourself or to another person.
- All the information collected from today will be stored on a computer with each person identified only by a number code. Only the researchers involved in the study will be able to view the information and when this information is used in future reports and publications no one will be able to recognise you from the information.
- Are you willing for me to record our conversation so that I don't have to write while we are talking? Nobody outside the research team will hear the tapes, and back at the University the tapes will be kept in a locked filing cabinet
- To make the research most useful, I need to know both positive and negative things so please don't hesitate to tell me if you have any problems to report. The comments from everyone who is interviewed are combined anonymously when the results are reported so no one can be identified.

1. Child and Adolescent services – entry, illness course and overall experience

Could you tell me the story about how you first came to see someone at the Child and Adolescent Mental Health Services?

(Prompts: Who asked you to be seen there and why?

How old were you?)

Could you tell me about your experiences of using Child and Adolescent Mental Health Services?

(Prompts: What happened at CAMHS?

Was there anything helpful?

Was there anything unhelpful?

Is there anything you would change?)

2. Transition Planning

How did you realise that you would have to move from the Child and Adolescent Mental Health Services to the Adult service?

Was there anything that helped or was unhelpful in preparing you for this move?

Thinking back, is there anything that would have been more helpful in preparing you for the move, or anything that you would change?

3. Transition issues

What do you think were the main reasons why you were referred to adult services?

Was the reason something that makes sense to you?

Thinking about you and your family, what would be good reasons for you to move from the Child and Adolescent Mental Health Services to the Adult services?

4. Adult services – entry, engagement and defaulting, and overall experience

Have you been to the adult service you were referred to?

(Prompts: If so 'in what ways?'

If no, 'why not?')

What has it been like going there?

5. Comparison of Adult to Child and Adolescent services

Are there any ways in which it has been better/easier/more helpful going to the adult service than CAMHS?

Are there any ways in which CAMHS was better/easier/more helpful than going to than the Adult service?

6. Potential impact of transition

In your opinion, has the process of changing from CAMHS to AMHS had any effect on you?

(Prompts:

Independence from parent

Engagement with services

Understanding of problems

Effects on severity of mental health problems-Better?, Worse?,

Any new problems?

What are you doing now? (college/working/hobbies, etc)

Is there anything else you would like to say about the transition from CAMHS to adult services that we haven't talked about yet?

Appendix 6: Stage 4 interview schedule for parents

Topic List: Interview Schedules for Carers

Introduction

Thank you for agreeing to be interviewed today. My name is _____ and I'm a researcher based at _____. We are doing a study looking at what happens when a person who is attending a child and adolescent mental health clinic, has their care transferred to an adult mental health service.

As your child has moved from one service to another in the past two years we would like to talk to you today about your and [name of service user] experiences of mental health services and the time when he stopped going to Child and Adolescent Mental Health Services. This will help us to develop ideas on how to improve services, especially for people who may have to move from one service to another in the future and their carers.

Schedule for carer

- I would like to remind you that everything that you tell me will remain anonymous. All the information collected from today will be stored on a computer with each person identified only by a number code. Only the researchers involved in the study will be able to view the information and when this information is used in future reports and publications no one will be able to recognise you from the information.
- Are you willing for me to record our conversation so that I don't have to write while we are talking? Nobody outside the research team will hear the tapes, and back at the University the tapes will be kept in a locked filing cabinet
- To make the research most useful, I need to know both positive and negative things so please don't hesitate to tell me if you have any problems to report. The comments from everyone who is interviewed are combined anonymously when the results are reported so no one can be identified.

1. Child and Adolescent Mental Health services – entry, illness course and overall experience

Could you tell me the story about how X first came to see someone at the Child and Adolescent Mental Health Services?

(Prompts: What was the problem?

Who asked him/her to be seen there and why?

How old was s/he?)

Could you tell me about your and X's experiences of using Child and Adolescent Mental Health Services?

(Prompts: What happened at CAMHS?

Can you think of anything particularly helpful?

Anything you found unhelpful?

Is there anything you would change?)

2. Transition Planning

How did you realise that X would have to move from the Child and Adolescent Mental Health Services to the Adult service?

Was there anything that helped or was unhelpful in preparing X and you for this move?

Thinking back, is there anything that would have been more helpful in preparing you and X for the move?

3. Transition issues

What do you think were the main reasons why X was referred to adult services?

Was the reason something that makes sense to you?

Thinking about X and your family, what would be good reasons for X moving from the Child and Adolescent Mental Health Services to the Adult services?

4. Adult services – entry, engagement and defaulting, and overall experience

Have you or X been to the adult service X was referred to?

Prompts: If so 'in what ways?'

If no, 'why not?'

What has it been like going there?

5. Comparison of Adult to Child and Adolescent services

What have you found to be the main differences in adult services as compared to the child and adolescent services?

Are there any ways in which it has been better/easier/more helpful going to the adult service than CAMHS?

Are there any ways in which CAMHS was better/easier/more helpful than going to than the Adult service?

6. Potential impact of transition

In your opinion, has the process of changing from CAMHS to AMHS had any effect on you or X?

Prompts:

Independence from parent

Engagement with services

Understanding of problems

Effects on severity of mental health problems-Better?, Worse?,

Any new problems?

Is there anything else you would like to say about the transition from CAMHS to adult services that we haven't talked about yet?

Appendix 7: Stage 4 interview schedule for CAMHS clinicians

Topic List: Interview Schedule for CAMHS Key-workers

Introduction

Thank you for agreeing to be interviewed today. My name is _____ and I am a researcher based at _____. We are doing a study looking at what happens when a person, who is attending a child and adolescent mental health clinic, has their care transferred to an adult mental health service.

As your client has moved from one service to another in the past couple of years we would like to talk to you today about your and your client's experiences of mental health services and the time when your client stopped going to Child and Adolescent Mental Health Services. This will help us to develop ideas on how to improve services, especially for people who may have to move from one service to another in the future and their carers.

- I would like to remind you that all the information obtained in this study will be entirely confidential. It will be stored on a computer with each person identified only by a number code. Only the researchers involved in the study will be able to view the information and when this information is used in future reports and publications no one will be able to recognise you from the information.
- Are you willing for me to record our conversation so that I don't have to write while we are talking? Nobody outside the research team will hear the tapes, and back at the university the tapes will be kept in a locked filing cabinet
- To make the research most useful, I need to know both positive and negative things so please don't hesitate to tell me if you have any problems to report. The comments from everyone who was interviewed are combined anonymously when the results are reported so no one can be identified.

1. Transition Planning

Could you tell me what your service did once it was decided [name of service user] needed to transfer to another service?

(Prompts:

- *How did you go about making the referral?*
- *Which service were they transferred to? Why?*
- *What is your ideal of a good transfer of care? Which aspects did X receive/not receive?*
- *Any difficulties in accessing this service?*
- *What did CAMHS do to help client with transition?*

2. Transition issues

What were the main reasons why X was referred to you?

(Prompt: Appropriateness?)

3. Comparison of Adult to Child and Adolescent services

To your knowledge are there any differences in the service [name of service user] receives in adult services when compared with CAMHS?

(Prompts in terms of:

- *Accessibility (out of hours/emergency contact)*
- *Continuity of care (seeing the same individuals, keyworker contact, being able to form a therapeutic relationship with the client)*
- *Quality of care (the benefits of any interventions offered, the quality of information and care given)*
- *Their diagnosis*
- *The types of staff they see*
- *Types of intervention)*

What services do you expect X to receive in adult service?

4. Potential impact of transition

In your opinion, has the process of changing from CAMHS to AMHS had any effect on [name of service users]?

(Prompts:

Independence from parents, engagement with services, understanding of problems and effects on severity of mental health problems-Better?, Worse?, Any new problems?)

Is there anything else you would like to mention that we haven't talked about yet?

Appendix 8: Stage 4 interview schedule for AMHS clinicians

Topic List: Interview Schedules for AMHS Care-coordinator

Introduction

Thank you for agreeing to be interviewed today. My name is _____ and I am a researcher based at _____. We are doing a study looking at what happens when a person who is attending a child and adolescent mental health clinic has their care transferred to an adult mental health service.

As your client has moved from one service to another in the past two years we would like to talk to you today about yours and your client's experiences of mental health services and the time when your client stopped going to Child and Adolescent Mental Health Services. This will help us to develop ideas on how to improve services, especially for people who may have to move from one service to another in the future and their carers.

- I would like to remind you that all the information obtained in this study will be entirely confidential. It will be stored on a computer with each person identified only by a number code. Only the researchers involved in the study will be able to view the information and when this information is used in future reports and publications no one will be able to recognise you from the information.
- Are you willing for me to record our conversation so that I don't have to write while we are talking? Nobody outside the research team will hear the tapes, and back at the University the tapes will be kept in a locked filing cabinet
- To make the research most useful, I need to know both positive and negative things so please don't hesitate to tell me if you have any problems to report. The comments from everyone who is interviewed are combined anonymously when the results are reported so no one can be identified.

1 Transition Planning

Could you tell me what happened once it was decided [name of service-user] would come to your service?

(Prompts:

- *Any discussion between you and your client's key-worker/staff at CAMHS?*

- *Was anything else done (e.g. Discussion with client? giving written information to the client?, or arranging a visit/a period of joint-working?*
- *Could anything else have been done?).*

2 Transition issues

What were the main reasons why X was referred to you?

(Prompt: Appropriateness?)

3 Comparison of Adult to Child and Adolescent services

To your knowledge are there any differences in the service [name of service user] receives in Adult services when compared with CAMHS?

(Prompts in terms of:

- *Accessibility (out of hours/emergency contact)*
- *Continuity of care (seeing the same individuals, key-worker contact, being able to form a therapeutic relationship with the client)*
- *Quality of care (the benefits of any interventions offered, the quality of information and care given)*
- *Their diagnosis*
- *The types of staff they see*
- *Types of interventions)*

4 Potential impact of transition

In your opinion, has the process of changing from CAMHS to AMHS had any effect on [name of service user]?

(Prompts:

Independence from parents,

engagement with services,

understanding of problems

effects on severity of mental health problems-Better?, Worse?

Any new problems?)

Is there anything else you would like to mention that we haven't talked about yet?

Disclaimer:

This report presents independent research commissioned by the National Institute for Health Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, the NIHR SDO programme or the Department of Health. The views and opinions expressed by the interviewees in this publication are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, the NIHR SDO programme or the Department of Health"

Addendum:

This document is an output from a research project that was commissioned by the Service Delivery and Organisation (SDO) programme, and managed by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO), based at the London School of Hygiene & Tropical Medicine.

The management of the 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. Although NETSCC, SDO has conducted the editorial review of this document, we had no involvement in the commissioning, and therefore may not be able to comment on the background of this document. Should you have any queries please contact sdo@southampton.ac.uk.