# Improving Mental Health Pathways And Care for Adolescents in Transition to Adult Services in Northern Ireland (IMPACT)


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## Abbreviations

| | |
|---|---|
| **A&D** | Armagh & Dungannon |
| **ADHD** | Attention Deficit Hyperactivity Disorder |
| **AMHS** | Adult Mental Health Services |
| **ASD** | Autistic Spectrum Disorder |
| **B&SE** | Belfast and South East |
| **BME** | Black and Minority Ethnic |
| **C&B** | Craigavon & Banbridge |
| **CAF** | Children's Assessment Framework |
| **CAIT** | Crisis Assessment and Intervention Team |
| **CAMHS** | Child and Adolescent Mental Health Services |
| **CFC** | Child and Family Clinic |
| **CI** | Co-Investigator |
| **CIS** | Critical Interpretive Synthesis |
| **CPA** | Care Programme Approach |
| **CVS** | Community and Voluntary Sector |
| **D&L** | Down & Lisburn |
| **DAH** | Developmentally Appropriate Healthcare |
| **DAMHS** | Drug and Alcohol Mental Health Services |
| **DNA** | Did Not Attend |
| **ED** | Emergency Department |
| **EDYS** | Eating Disorder Youth Service |
| **EIS** | Early Intervention Services |
| **EIT** | Early Intervention Team |
| **GP** | General Practitioner |
| **HSCB** | Health and Social Care Board |
| **HSCT** | Health and Social Care Trust |
| **JCPMH** | Joint Commissioning Panel for Mental Health |
| **LAC** | Looked After Children |
| **N&M** | Newry and Mourne |
| **ND&A** | North Down & Ards |
| **NI MDM** | Northern Ireland Multiple Deprivation Measure |
| **NISRA** | Northern Ireland Statistics and Research Agency |
| **PMHT** | Primary Mental Health Team |
| **OREC** | Office Research Ethics Committee |
| **RCT** | Randomised Control Trial |
| **RL** | Retain Lead |
| **SCIE** | Social Care Institute for Excellence |
| **SED** | Serious Emotional Disorder |
| **SHSCT** | Southern Health and Social Care Trust |
| **SMC** | Serious Mental Conditions |
| **SMT** | Senior Management Team |
| **SEHSCT** | South Eastern Health and Social Care Trust |
| **SU** | Service Users |
| **TIP** | Transition to Independence Process |
| **TL** | Transfer Lead |
| **YAS** | Young Adults Service |
| **YP** | Young Person |
| **YPC** | Young People's Centre |
| **YTP** | Youth Transition Programme |

## Terminology used in the report

| Term | Meaning |
|---|---|
| **Service provider** | Professional staff working in CAMHS or AMHS |
| **Informal carers** | The informal carers is parent or guardian usually the primary carer |
| **Looked After Children /Young people** | Children or young people in public care |
| **Professional carers** | Staff with regular contact with service user and family e.g. consultant psychiatrists, psychologists and social workers |
| **Scoping review** | A scoping review is an exploratory review that is predominantly rigorous and explicit yet is not fully systematic in its methods. |
| **Systematic review (SR)** | SR is the systematic search for an appraisal of evidence from primary studies to answer sharply defined research questions. SR provides concise summaries of the best available evidence. |
| **Transition** | Transition is the purposeful, planned process that addresses the medical, psychological and educational/vocational needs of adolescents and young people with chronic physical and medical conditions as they move from child- centred to adult oriented health care systems |
| **Young person** | Any young person between the age of 16 and 25 |
| **Units** | Mental health teams e.g. CAMHS teams or AMHS teams |

# CHAPTER 1: INTRODUCTION AND BACKGROUND

## 1.1 Introduction to transitions during adolescence

Adolescence is a transitional period of life from puberty to adulthood, generally understood to cover 12 to 22 years, and characterised by marked physiological changes and the development of sexual feelings. It is typically regarded as a time of transition from childhood dependency to adult responsibility, when young people move from school into further or higher education, or into work or training These changes are also accompanied by efforts towards identity construction, a stage marked by young people's attempts to separate themselves from their parents but lacking any clearly defined role in society. Thus, it is generally regarded as an emotionally intense and often stressful period. Importantly, some young people are more resilient and better equipped, socially and emotionally, to deal with adversity and the key transitions of adolescence.

### *1.1.1 Young people and mental health*

The rates of mental health problems increase during adolescence. Recent epidemiological studies (Meltzer et al. 2003) highlight that increasing numbers of children and young people experience poor mental health, with prevalence rates of between 20 and 25% of mental disorder being reported in the general population of children and young people worldwide (Gore et al. 2011, Patel et al. 2007). Other evidence suggests that 50% of adolescents may be at moderate to high risk of adverse health outcomes due to risk-taking sexual behaviour, psychosocial problems, substance abuse and life style choices (Anderson et al 2010; Brindis et al 2002; Brindis et al 2007). Late adolescence and early adulthood is recognised as a time of increased risk for developing mental health problems such as depression (Goodyer et al., 2009), with research suggesting that approximately half of all mental disorders begin in middle teenage years and three quarters by the mid-twenties (Kessler et al, 2007). Some more serious disorders, such as psychosis, emerge during this period (Singh 2010a; Reale and Bonati 2015). Young people with mental illnesses face greater challenges in the transition to adulthood than their peers without illnesses, and demonstrate poorer transition related outcomes (e.g., high dropout rates, unemployment, involvement in the criminal justice system, early and unplanned pregnancies, and homelessness) compared to peers in general and youth with other disabilities (Wagner et al. 2005).

Mental illness frequently starts in childhood and during the teenage years. The ages 16–18 are a particularly vulnerable time when the young person is both more susceptible to mental illness, is going through a period of physiological change, and is making important transitions in their education (The Joint Commissioning Panel for Mental Health (JCPMH) 2012). As

described above, approximately a quarter of 16-24 year olds have mental health problems (Social Exclusion Unit, 2005; Gore et al., 2011, Patel et al., 2007).

The JCPMH (2012) identified groups of young people at particular risk of experiencing poor mental health:

- young people in contact with the juvenile justice system, where the rates of mental health problems are at least three times as high as within the general population (Fazel & Benning, 2009; Ahrens et al., 2008 cited by Christian & Schwarz 2011)
- young people in care are at fivefold increased risk of childhood mental disorder (Meltzer et al 2003), and have increased risk of suicide attempt as an adult (Vinnerljung et al., 2006)
- young people and children with learning disability have an increased risk of mental health problems (Emerson & Hatton, 2007)

While little epidemiological data exist on the mental health of children and young people living in Northern Ireland, it is estimated that the rates of mental disorder are at least comparable to those reported for Great Britain and may be higher, taking into account the higher levels of socio-economic deprivation, the legacy of the conflict (Gallagher, 2004) and higher rates of psychiatric morbidity in the adult population in Northern Ireland (McConnell et al., 2002).

In the 2009 Young Life and Times survey, 29% of 16 year old respondents reported serious personal emotional or mental health problems, with a much higher percentage (43%) from 'not well off backgrounds' doing so (Schubotz & McMullan, 2010). The number of young people, particularly young men who die by suicide in Northern Ireland has increased steadily over recent years. Across the UK, Northern Ireland has the second highest suicide rate per 100,000 of the population, (278 recorded deaths in 2012).

It is estimated 10% of young people aged 15 and 16 years have self-harmed (O'Connor et al. 2014). A recent review of case studies of suicides of young people in Northern Ireland (Devaney et al 2012) found

> *"...some young people were caught in the transition to adult services, often experiencing long delays before help was offered. Adult mental health services often place the onus on the patient to follow up missed appointments and there was a lack of recognition that some young people may need help to attend, especially in the period of transition between children's and adult services"* (Devaney et al (2012) p.70)

### *1.1.2 Transitions from children's to adults' services*

Transition is defined as a purposeful and planned process of supporting young people to move from children's to adults' services (DH & DfES 2006). The transition from Children and Adolescent Mental Health Services (CAMHS) to Adult Mental Health Services (AMHS) is a major concern for many young people, their parents/carers and for service providers (Department for Health & Department for Children, Schools and Families 2008a). In England, young people with severe mental disorders such as psychosis are more likely than other young people with neuro-developmental, emotional/neurotic and personality disorders to transition to adult services (Singh et al., 2010a), and up to a third of young people are lost from care during transition and a further third experience an interruption in their care.

Poorly planned transitions from young people's to adult oriented services can be associated with increased risk of non-adherence to treatment, loss to follow-up (DH & DES 2006), and poorer health outcomes (Harpaz-Rotem et al., 2004; Memarzia et al 2015). Over the past decade, considerable attention has been given to transition from children's to adult health services across a range of chronic conditions (e.g. Department of Health (2006); DH and DCSF (2008a, 2008b), Royal College of Nursing (2013), Royal College of Physicians of Edinburgh (2008). The Intercollegiate Working Party on Adolescent Health (Royal College of Paediatrics and Child Health (RCPCH) 2003) describes transition as a multidimensional process that continues into adult care marked by joint responsibilities and multidisciplinary working, and recommends that:

> *'For young people with mental health problems specific services should be available for those in the 16-19 gap.* (RCPCH 2003 p.40)

Moreover, evidence also suggests that between 30-60% of young people drop out of treatment with young socially isolated males most likely to disengage (Harpaz-Rotem et al 2004). Many of these young people come into contact with services later, including the criminal justice system, with complex, compounded and harder to manage problems. Thus, the costs incurred by poor engagement and untreated adolescent mental illness are considerable, impacting as they do on the individual, their families and communities (Knapp et al. 2002). More widely there are considerable costs to education, employment, health, welfare and the criminal justice system (Stengård & Appelqvist-Schmidlechner 2010; Suhrcke et 2007).

Good transitions can improve longer terms health outcomes, and have also been found to result in savings for adult health services. A study by PriceWaterhouseCoopers (PWC) analysed the long term costs of current transitions versus 'optimal' transitions from CAMHS to adult services in Coventry (PWC cited by NMHDU 2011). An actuarial model informed by the international research evidence about what works was developed to track process steps within

organisations and care pathways. PWC found that improving transitions for adolescents led to long term savings for adult service users as well as improved user outcomes. (A fuller summary of the international research evidence is presented in Chapter 6 of this report).

## 1.2 The IMPACT study

In 2006, the Bamford Review (2006) set out a strategic vision for the development of a service for children and young people with mental health problems (see Chapter 6 & Appendix 2 for fuller details on the Bamford Review and relevant Northern Ireland Policy and Legislation). The review highlighted concerns that CAMH services in NI may be under resourced, patchy and inconsistent in their approach to adolescent care and service transition. It questioned the strength of effective liaison and collaboration between services such as Adult Mental Health Services (AMHS), education, social services, criminal justice and primary care. It also noted that in relation to Tiers 1 & 2 (see Figure 3.2, in Chapter 3, for further details on the different tiers), there has been a notable failure to engage with the education and voluntary sectors of which "*many of these services and projects do not yet conceptualise themselves as part of CAMH services*". Others have argued that CAMHS and AMHS are overly rigid in defining the appropriate age cut-offs to demarcate service territory, cut-offs that often do not reflect individual emotional development or needs (Singh 2009). Significantly, there is no consensus as to where CAMHS ends and AMHS begins, with variable cut-offs in the UK between 16 and 18 years and although transition policies advocate flexibility, anecdotal evidence suggests otherwise; that is, holistic approaches tend to get jettisoned when services are under pressure in order to maintain manageable caseloads. The ethos, culture and practice in CAMHS appear to have evolved somewhat differently to adult services (see Chapter 6 for further detail on the different care philosophies). Differences have been noted in the theoretical and conceptual views of diagnosis and treatment and these, oppositional perspectives, create barriers at the interface for young people in transition. McGorry has suggested that statutory 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*" (McGorry 2007). Thus, many young service users and their families may be needlessly distressed. As a result there has been concern that many young people with mental health problems are being lost to care in the move from child and adolescent mental health services to adult mental health services.

Despite these consequences, as Singh et al. outline, *"there is very little evidence about the magnitude of the problem, outcomes of people who fall through such care gaps, interventions that might improve the process, and the experiences of service users and carers about transition"* (Singh et al. 2005).

The IMPACT study was commissioned to gain a greater insight into the transition from CAMHS to AMHS in Northern Ireland, to gain different perspectives of the transition experience, and to explore how the needs of young people from different backgrounds are accommodated. The study also explores the needs of young service users in terms of recovery "*to hear their experiences and aspirations and translate these experiences into service design, planning, commissioning and delivery. People who use services and their family members will be involved in the planning, commissioning and implementation of services*" (Social Care Institute for Excellence (SCIE), 2007: p20). 1: p20).

Using a similar methodology to the TRACK in England (Singh et al. 2010) and the ITRACK in the Republic of Ireland (McNamara et al. 2013), the study provides baseline data for future national/inter-island service evaluation. However, it is important to note that services in Northern Ireland, and the populations served by them, differ significantly from those evaluated in England by TRACK study. For example, the NI population is more rural and relatively ethnically white.

# CHAPTER 2: THE IMPACT STUDY DESIGN

## 2.1 Overview of the study design

This chapter presents a brief overview of the design and conduct of the IMPACT study. The research was conducted over a 3-year period and involved four stages: a mapping study, case note reviews, and in-depth interviews with service users, parents/carers, and an evidence review (see Table 2.1 below for a summary). The study employed a mixed methods design, involving quantitative data collection from case-notes, interviews, focus groups/workshops and a self-completion survey, designed to address each of the research questions. Using the mixed methods design, the approach is underpinned by concepts within critical realism (Pawson and Tilley 1997, 2004) and evaluation frameworks which attempt to uncover influential processes, policies, perceptions and events that often determine the outcomes of service development. Quantitative and qualitative data are integrated and presented to accurately reflect the full range of stakeholder experiences and perspectives. The findings are sequentially tested and refined our theoretical assumptions about the transition pathway and the constituent factors underlying barriers and facilitators to good care.

## 2.2 Study aim and research questions

The primary aim of the IMPACT study was to gather robust data on the provision of services for adolescents in NI during the transitional stage from CAMHS to AMHS which will inform service review and development

The study had one overall question and 4 subsidiary questions driving the research process.

1. What is the best way to organise mental health services for young people (YP) in Northern Ireland (NI) as they make the transition from Child and Adolescent Mental Health Services (CAMHS) to Adult Mental Health Services (AMHS)?
    a. How do mental health services in the Health and Social Care Trusts in NI differ in their policies and provision of care for young people in the transition to adult services?
    b. How does social disadvantage influence health pathways and outcomes among young people?
    c. Which factors influence adolescents' engagement with services and continuity of care?
    d. What are the barriers and facilitators to CAMHS collaboration with adult mental health service, primary care and relevant community based agencies?

Reflecting the focus of each research question, different methods were used for each stage of the research. Chapters 3-6 provide specific detail on the research methods involved for each particular stage of the study.

Table 2.1: Summary of the 4 stages of the research

| Stage | Approach | Number of participants |
|---|---|---|
| **Stage 1** | Mapping of services and interviews with service providers<br><br>Feedback workshop with service providers and service users | **Service Mapping**: All five trusts<br>13 mapping tools completed<br>BHSCT 6, SEHSCT 2, SHSCT 3, NHSCT1 (representing 3 teams), WHSCT1 (representing 2 teams)<br><br>**Interviews and focus groups** N=149<br>***Individual interviews***<br>*Statutory* Services n=8<br>CVS n=14<br>***Focus groups & meeting***<br>2 transition panel meetings (n=21)<br>4 academic meetings (n=80)<br>3 staff team meetings (1 AMHS CMHT, 2 CAMHS) (n=26)<br><br>**Interactive Workshop N=41 attended**<br>4 focus groups (n=32) |
| **Stage 2** | Case note review | N=373 cases |
| **Stage 3** | Interviews with current and past service users<br><br>Interviews with parents/carers<br><br>Interviews with clinical service providers | **Young people** N=25<br>Current service users n=18 (Core group) **<br>(**Follow-up interviews n=10)<br>Service users with transition experience (supplementary sample) n=7<br><br>**Individual interview with parents/carers** N=12<br>Includes interviews with parents of core group n=7<br>Individual interviews with parents/carers of children who had recently made the transition (but were not part of the core group) n=5<br><br>Plus 1 focus group interview with parents/carers n=5<br><br>**Mental Health Professionals** N=26<br>Includes interviews with keyworkers of core group n=18 and interviews with staff from Primary Care Liaison, Recovery College, Addiction Team, CAMHS/AMHS psychiatry n=8 |
| **Stage 4** | Rapid evidence review | Not relevant |

## 2.3 Ethical approval and research governance

An application for ethical approval was submitted to the Office Research Ethics Committee (OREC) Northern Ireland, to include site specific governance approval from each of the NI HSC Trusts. The application received a favourable outcome, and was approved by the Ulster University Research Governance office, which also granted a Statement of Indemnity.

A steering committee, comprising Consultant Psychiatrists, academics and researchers generally met bi-monthly throughout the project, and informed all aspects of the project.

## 2.4 Participant recruitment

The CAMHS team in each of the NI NHS Trusts was contacted to inform them of the project and requesting assistance with recruitment to the study. In addition, a meeting was convened with the Senior Management Teams (SMT) in each Trust to secure their support for the project[i]. Support was also provided by the Royal College of Psychiatrists in NI, which provided considerable support by encouraging the involvement of trainee psychiatrists (locating at least one trainee per trust area) in the data collection process. The trainees assisted us by contacting service teams and helping with recruitment. A Consultant Psychiatrist who was a Principal-Investigator and member of the steering group committee provided information and advice throughout the study. Local Principal-investigators assumed responsibility for the activities of the research team within each of the Trusts. Fuller details of the recruitment procedures involved for each stage of the research is provided in Chapters 3-5.

## 2.5 Data management and confidentiality

Interviewees from all stages of the research were given a code number in addition to a pseudonym. It was necessary to keep contact details of service users, however real names, pseudonyms and identification numbers were kept in separate files. In order to protect participant anonymity, findings from the qualitative interviews do not provide information of geographic location or Trust details. For the case note review, no names were recorded on the forms (see Chapter 4 for further detail).

All data was kept in a secure place and controlled by a named researcher. Additionally, written informed consent was sought from all the participants in the qualitative elements of the study. All audio-recorded qualitative interviews were 'wiped' following transcription and any identifying text removed.

## 2.6 Data analysis

Full details of the analytical approach adopted for each stage of the research is presented in Chapters 3-6. Below is an overview of the approach to data analysis.

### *2.6.1 Qualitative data analysis*

All interviews from each stage of the research were recorded and transcribed for entry on NVivo (a software programme designed to assist management and analysis of large quantities of text data). The anonymised data were coded and thematically analysed for patterns relevant to the stage of the research.

### *2.6.2 Quantitative data analysis*

Data were recorded in either categorical, numerical or text form. The dataset collected from the initial case audit allowed us to ascertain what difficulties services face around the transition period. The transitions were evaluated according to whether they were considered 'optimal' or 'suboptimal' using TRACK definitions which were derived from a combination of protocol content analysis and literature on continuity of care (Burns et al 2007). Descriptive analysis using SPSS (Statistical Package for Social Sciences) were conducted to determine rates and proportions of successful and unsuccessful transitions for each service type and illustrate existing pathways of transition. Logistic regression was used to examine the likely contributing factors that best characterise differences between those who transition and those who do not. In addition a latent class analysis was undertaken in order to examine the various profiles of those presenting to the services.

## 2.7 Presentation of study findings

The report is structured to present the key findings from each stage of the research before providing a synthesis of the overall study findings with recommendations for policy, research and practice.

**Chapter 3**: Mapping of services involving a survey of all CAMH services across the five health and social care trusts in NI to describe:

a. The structure of the CAMH services
b. Caseloads and staffing levels
c. Transition boundaries
d. Referrals to adult services
e. The transition process

**Chapter 4**: Findings from the case note reviews of:

a. Pathways and outcomes of young people attending CAMH services in NI over a 48-month period and who meet the criteria for transition from CAMHS to AMHS (All Trusts)
b. Pathways and service destinations of *all* young people accepted by CAMHS aged 16+ over a 48-month period (Belfast & Eastern Trust area only)

**Chapter 5**: Findings from the qualitative research, which included:

a. Focus groups with CAMHS and AMHS multi-disciplinary teams, managers and commissioners in each Trust (conducted as part of the service mapping)
b. In-depth interviews with relevant agencies and professionals external to statutory mental health services

c. In-depth interviews with Service Users (SUs), their parents/carers and professionals to explore their experiences during the transition from CAMHS
d. An interactive workshops with service users, clinicians and other stakeholders to synthesise and report on the findings, and to gain participants' feedback and their views on recommendations for service improvement

**Chapter 6**: Findings from a rapid review of the international evidence on the transition from CAMHS to AMHS.

**Chapter 7**: Discussion and recommendations.

# CHAPTER 3: STAGE 1 MAPPING OF SERVICES

## 3.1 Aim

The aim of the service mapping stage of the research was to describe mental health services in the Health and Social Care Trusts in NI, and to explore how each trust differs in their policies and provision of care for young people in the transition to adult services (Research Question 1a). Before presenting the methods and findings from this stage of the research, we provide an overview of the overall organisation and structure of CAMHS in Northern Ireland.

The specific aim of the mapping exercise was to gather data from each Trust on:

- The structure of CAMH services
    - The interface between CAMHS, adult services and social services
    - Collaboration and liaison between CAMHS and the voluntary sector
- Numbers of patients transferred to adult services in previous 12 months
    - criteria and cut-offs determining boundaries
- Approaches to transition
    - Written policies about transition
    - Single/shared/multiple protocols
    - Jointly devised strategies for managing the interface
    - Transition models

## 3.2 Methods

Two approaches were used in this stage of the research: (a) a survey of the 16 mental health units, and (b) individual and focus group interviews with staff members of the CAMHS and AMHS teams, as well as representatives from the Community Voluntary Sector (CVS).

### *3.2.1 Survey of Mental Health Units*

All CAMH services were identified through the Trust personnel collaborating on the study. A service was defined as an agency that provides CAMHS Tier 2/3/4 service (see Figure 3.1, above, for more information on the tier system). A copy of the IMPACT Mapping Tool (see Appendix 3) adapted from the TRACK tool (Singh 2008), was sent by email to all CAMHS Children's Services Managers, Clinic Managers, or Team Managers in each Trust. As the RQIA (2011) report indicated differences in the content of such protocols and their usage, data were gathered on: (a) the structure of CAMHS; (b) the interface between CAMHS, adult services and social services; (c) collaboration and liaison between CAMHS and voluntary services; (d) criteria and cut-offs determining boundaries; (e) written policies about transition; (f) jointly devised strategies for managing the interface; (g) numbers of patients transferred to adult services in previous 12 months; (h) identification of any existing single/multiple/shared

protocols within/between CAMHS and relevant AMHS (and any gaps), i.e. geographical coverage of transition protocols; and (i) implementation of existing transition models, e.g. specific transition teams, transition workers. As part of the service mapping survey, teams were asked to forward any polices, guidelines or protocols used to manage the transition or the interface between CAMHS and Adult services. In addition, the researchers undertook data collection during a visit to each site.

The mapping tool was completed by 13 managers on behalf of the 16 teams (2 managers completed the mapping tool as a composite on behalf of all teams within their trust, whilst individual responses were returned for each CAMHS team in the remaining trusts). Six tools were returned from the Belfast Health and Social Care Trust (BHSCT) (largely defined by specialism), two from the South Eastern Trust (defined by locality), three from the Southern Health and Social Care Trust (SHSCT) (defined by locality) and one each from the Northern Health and Social Care Trust (NHSCT) (on behalf of the three local teams) and the Western Health and Social Care Trust (WHSCT) (on behalf of the two local teams). All five Trusts returned their most recent transition protocol.

### *3.2.2 Focus groups and interviews with service providers*

During the course of the project, a series of focus groups and individual interviews were conducted with staff teams in CAMHS and AMHS. For each focus group, a topic guide was used (Appendix 4a). The guide included generic service related questions germane to all teams and site-specific questions that related to areas and issues that were highlighted by the RQIA report and our internal survey. The purpose of the focus groups was to uncover 'real world' factors that undermine or assist positive transitions; for example, the extent to which referral decisions derive solely from clinical need or alternatively, were in response to financial pressures.

Representatives from the Community and Voluntary Sector (CVS) across the region were also invited to participate in the study. These third sector organisations were either (a) identified by staff in the statutory services as providing relevant services to young people, or (b) were named on the Trusts' websites as alternative sources of support. The interviews with the CVS representatives used the same informed consent procedures as with the statutory sector but with a separate topic guide (Appendix 3b).

### *3.2.3 Profile of participants in interviews and focus groups (Stage 1)*

As described above, individual and focus group interviews were held with CAMHS and AMHS clinicians, managers, and staff teams to build a picture of the transition process across the five Trusts. In all, nine focus groups (comprising of 127 participants) were held as part of this process. Individual interviews were also conducted with representatives (n=14) from the

Community and Voluntary Sector (CVS) across the region. Nine multidisciplinary focus group interviews were held with:

- Two Transition Panel Meetings (totalling 21 representatives from CAMHS and AMHS);
- Four academic meetings (primarily attended by Psychiatrists from AMHS n=80+)
- Three staff team meetings (1 AMHS CMHT, 2 CAMHS team meetings, n=26)

The material from the focus groups and individual interviews are integrated within Chapter 5 of this report.

In addition to the above, at the end of the project, forty-one people in total attended the workshop, ten of whom worked within CAMHS, ten within AMHS, ten within the Community and Voluntary sector and eleven others comprising service users, carers, advocates, researchers, and commissioners. From these 41 participants, 32 participated in one of the four focus groups as part of the interactive workshop. Table 3.1, below, presents a summary of the profile of participants in the focus groups.

**Table 3.1**: Numbers and profile of participants in interviews / focus groups (service providers)

| PARTICIPANTS | CAMHS | AMHS | Both CAMHS & AMHS | CVS | Total participants |
|---|---|---|---|---|---|
| Individual Interviews | n=4 | n=4 | - | n=14 | n=22 |
| Multidisciplinary Group interviews | 2 (n=17) | 1 (n=9) | 6 (n= 101) | | n=127 |
| Interactive workshop | | | 4 (n=32)* | | n=32 |
| Total | n=21 | n=13 | n=133 | n=14 | N=181 |

* The interactive workshop included service users, parents/carers and policy makers

## 3.3 Data analysis (Stage 1)

The information returned in the mapping tools and the protocols were subjected to content analysis and the main themes identified. Where possible, data from the mapping tools are summarised for each trust area and presented in tabular format.

The recorded interviews and focus groups were transcribed and entered into NVivo. Data were thematically analysed for patterns that exist across all the CAMH services. We also explored successes and problems that emerge from a specific service or services. We were particularly interested in the appearance of residual difficulties that persist despite the existence of good practice guidelines and existing protocols.

The quantitative findings from the online survey to the workshop participants were analysed using Excel to provide descriptive summary of the feedback. The qualitative findings were thematically analysed and integrated with the other qualitative data. Findings from the

interviews and focus groups directly related to the service mapping are presented below. However, some of the findings on broader issues on transition are integrated within the findings from the interviews with service users and their carers and are reported in Chapter 5 of this report.

## 3.4 Findings

It is important to note that much of desk research for this part of the study was completed in 2013-2015, and content analysis was carried out on the latest tool issued to the project. During this time, transition protocols were under review in a number of the Trusts. **Thus, the mapping[1] exercise is not evaluative and does not claim to be a definitive account of services offering support in the mental health field in the region.**

The findings from the service mapping are organised as follows:

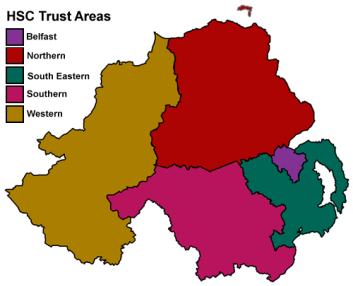
1. an overview of the CAMHS provision in Northern Ireland, including a description of the service structure in each Trust
2. detail on structure of CAMH services provided by the Belfast Health and Social Service Trust (BHSCT) followed by the remaining 4 Trusts
    a. CAMHS staffing and caseloads by Trust
    b. referrals, and interface with adult services and other sectors by Trust
    c. the transition process
3. content analysis of transition protocols and procedures used by practitioners (interview data).

### *3.4.1 Overview of the CAMHS provision in Northern Ireland*

In 2006, the Health and Social Care structures in Northern Ireland were reorganised into five Health and Social Care Trusts (HSCT), with the responsibility of assessing need (Figure 3.1) and the commissioning of services falling to a new Health and Social Care Board (HSCB). Since then, mental health hospital and community based services are delivered through the five integrated health and social care Trusts.

[1] *The information reported in this section is accurate only at the time of collection. The mapping tool was issued in 2015 and managers were asked to report figures for 2014*.

**Figure 3.1**: HSC Trusts in Northern Ireland[2]




The five Trusts serve a total population of approximately 1.8 million people, two thirds of whom live in Belfast and the Greater Belfast area (Table 3.2). One fifth of the total population are aged 15 years and under; 25% are aged between 16 and 34 years (NISRA[3]).

**Table 3.2** Estimated 2014 Population BY Trust

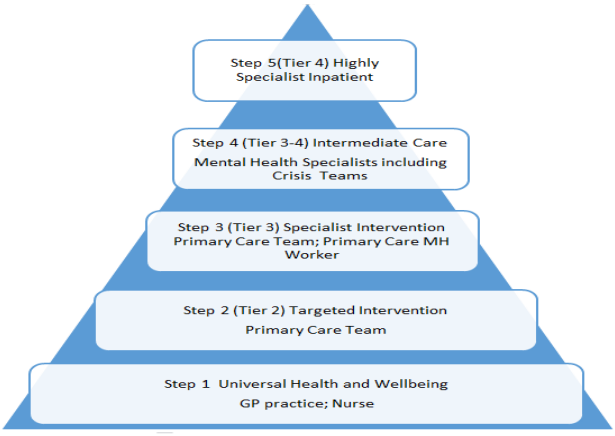
| Trust | Belfast | South Eastern | Southern | Western | Northern |
|---|---|---|---|---|---|
| Total Population | 351,554 | 352,301 | 369,391 | 298,201 | 469,051 |
| Total age 18 and under | 86,645 | 89,421 | 104,242 | 81,538 | 120,765 |
| **% Total u18** | **24.6%** | **27.4%** | **28.2%** | **27.3%** | **25.7%** |

Source NISRA[4]

The Stepped Care approach to care (see Figure 3.2) is designed to improve the provision of coordinated care across health, social care and specialist CAMHS (DHSSPS, 2012), and is delivered through four community based mental health teams within the five Trusts. Stepped Care means that when a person is referred to services they receive the care matched to their needs at that time, and will only be 'stepped up' to more specialised or intense care if the need arises. They can similarly be 'stepped down' as intervention is completed or intensive support is no longer required. The model was developed following the RQIA Independent Review of CAMHS in 2011 (See Chapter 6 for more information), which recommended that the Department of Health develop regional policy guidance to address the inconsistencies in structures and service provision identified across the health and social care trusts.

[2] Source: http://online.hscni.net/wp-content/uploads/2014/02/HSCTrustMap_500x400.png
[3] http://www.nisra.gov.uk/index.html
[4] http://www.nisra.gov.uk/demography/default.asp136.htm accessed Oct 2016

**Figure 3.2:** The Stepped Care Regional Model for Mental Health in Northern Ireland [5]




The overall aim of the CAMH service in Northern Ireland is to:[6]

- 'provide therapeutic help for children and young people (under 18 years of age) experiencing mental health difficulties
- promote the psychological, emotional and social development of children and young people within the context of their family and wider community'

Sixteen core teams deliver the service at a local level across the five HSC Trust areas. A core expectation within the Bamford Review's vision for mental health services was that young people with mental health needs be cared for within the community close to their family and friends, where clinically possible. In addition to these local community services, a number of services are also provided at a regional level, including inpatient adolescent unit at Beechcroft and the Family Trauma Centre.

The Family Trauma Centre provides specialist therapeutic service for children, young people up to 18 years, and their families following severe psychological trauma. It operates an open referral policy including self-referral, and covers all areas of Northern Ireland. Since 2010 inpatient care for children and young people is provided regionally at Beechcroft, the Child and Adolescent Inpatient Mental Health Unit located at the Forster Green site in Belfast. The unit has 33 beds, 18 for adolescents, two of which are designated as intensive care beds, and 15 for children. This inpatient service provides assessment and treatment at Tier 4 level for complex mental illness and children and young people regarded to be at acute risk, or those who cannot be 'assessed or safely treated in the community'.

[5] http://www.westerntrust.hscni.net/pdf/THRESHOLD_CRITERIA_FOR_SPECIALIST_CAMHS.pdf

[6] Mind Matters *'The Young Person's Guide to Child and Adolescent Mental Health Services in Northern Ireland'* http://www.belfasttrust.hscni.net/pdf/Mind_Matters_BSET.pdf

A service to support Trans and Gender Variant young people was set up as a regional service in Belfast in August 2014. Knowing Our Identity (KOI), a gender identity development service is based at Beechcroft, Forster Green site.

The Community Forensic Child and Adolescent Mental Health Service is a delivered by multi-professional team of health and social care and justice professionals for Northern Ireland. It was developed in partnership with the Youth Justice Agency (YJA). The service is a Step 5 CAMH service for young people up to and including 17 years old at the time of referral, living in NI, who present with 'severe disorders of conduct and emotion' or 'serious mental health problems' where the young person is involved in dangerous high-risk behaviours. Referrers retain overall clinical responsibility and steps are taken to ensure the young person's local Step 3 CAMHS team are involved. Guidelines for referrals to the regional specialist CAMH services are outlined in the document drawn up by the Trusts' CAMHS managers and the HSCB Commissioners, published in July 2012[7]. This document supports the implementation of the Regional Service Model, which was published in response to the RQIA CAMHS review in 2011. The Referral Guidelines document outlines the nature of problems specialist regional services will provide care for, and outlines the transitional arrangements for those who need to transfer to adult services.

### *3.4.2 Structure of the individual Trusts*

#### *Belfast Health and Social Care Trust (BHSCT)*

Child and Adolescent Mental Health Services in the Belfast Health and Social Care Trust are delivered through stepped care pathways. CAMHS in the Belfast Trust area is divided into two age cohorts, 0-14 and 14-18 years. The service for children aged 0-14 years is located at the Royal Hospital. Care is sometimes provided by this team for young people beyond the age of 14, if they show early signs of psychosis and a referral to the Early Intervention Team (EIT) is made directly at eighteen.

The Primary Mental Health Team (PMHT) provides a service for 'prevention and intervention' on a shorter time frame for young people with mild to moderate mental health problems. The team is located in the Young People's Centre (YPC) at College Gardens, Belfast. Step 3 Care is also provided at the YPC for young people aged 14-18 years with more complex mental health needs. Assessment and treatment for young people with ASD and co-morbid ADHD is also provided. A regular support group for parents of young people receiving care runs at the YPC.

The Drug and Alcohol Mental Health Service (DAMHS) is also located in the YPC at College Gardens. This is a specialised service for young people who have a 'significant substance

[7] http://www.westerntrust.hscni.net/pdf/THRESHOLD_CRITERIA_FOR_SPECIALIST_CAMHS.pdf

misuse problem and mental health difficulty,' and covers Belfast and the South Eastern HSCT area. The Eating Disorder Youth Service (EDYS), located at Beechcroft, also covers Belfast and South Eastern areas. It is a specialist outpatient service and provides support for children and young people, and their families.

The Crisis Assessment and Intervention Team (CAIT), developed in response to the increasing number of young people who self-harm, who attempt to take their own life or engage in high risk behaviour, serves the Belfast and South Eastern areas, and '*provide(s) rapid assessment and intervention to children and young people who present at A&E or GP with acute mental ill health, self-harm or suicidal ideation*'. Where possible, in order to prevent hospital admissions, intensive treatment is also provided in the community by the CAIT service. CAIT provides a prompt mental health assessment, same or next day, to children and young people who present at Emergency Departments (ED) or to their GP with suicidal ideation, self-harm or acute mental ill health. This service is ideally provided within the community through short term intensive intervention.

### *South Eastern Health and Social Care Trust (SEHSCT)*

In addition to the services managed by the Belfast Trust (described above), the South Eastern HSC Trust deliver child and adolescent mental health services through two local teams, North Down and Ards (DN&A), and Down/Lisburn (D/L). North Down and Ards serve a catchment population of 334,552 with Down/Lisburn serving a population of 295,513. The teams have partnerships with key clinicians in the Lagan Valley Hospital, Lisburn, the Ulster Hospital, Dundonald and the Downshire Hospital, Downpatrick and with GP practices across the area. The catchment area covers both urban and large rural areas, raising additional considerations for patients including transport and family links. At the time of data collection, the South Eastern sector was reviewing their transition policy and transition panel arrangements to include local considerations such as these.

### *Southern Health and Social Care Trust (SHSCT)*

CAMHS in the Southern Health and Social Care Trust (SHSCT) are organised into three locality teams: Armagh and Dungannon; Craigavon and Banbridge; and Newry and Mourne. Clinic Managers, detailing the service provided by each of the three teams, completed three individual Mapping Tools.

### *Northern Health and Social Care Trust (NHSCT)*

The Northern Trust is the largest Trust in the region. The Mapping Tool was completed by the Clinical Lead, who provided a composite return for the three teams in the trust. The CAMH service is organised into three teams covering three geographical areas, East Antrim Team, (Larne, Carrickfergus, Newtownabbey); the Antrim Team (Antrim and Ballymena); and the

Ballymoney Team (Coleraine, Ballymoney, Moyle, Magherafelt and Cookstown). As well as the three local CAMHS teams, the service also includes eating disorder and substance misuse teams organised on a Trust wide basis and located in Antrim.

### *Western Health and Social Care Trust (WHSCT)*

The Western Health and Social Care Trust CAMHS operates in two local teams: the Northern Sector which is based in Derry, covering Derry, Limavady and Strabane areas; and the Southern Sector, based in Omagh, with an outreach clinic in Enniskillen, and covers Omagh and Fermanagh. In 2014 the Western HSC Trust had an estimated population of 294,417 (NISRA, population estimates in 2014) of whom approximately 78,023 were under the age of 18. The restructuring of the service was completed in 2010 when CAMHS moved to an under 18 service. Prior to that date the cut off age was 16 years.

### *3.4.3 Staffing and caseloads by Trust*

The Mapping Tool sought to identify the staffing levels (by discipline) for each Trust. Tables 3.3 and 3.4 provide a summary of respondents' indications of the caseload and full time equivalent (FTE) staffing for the Belfast Trust and South East Sector. Tables 3.5 and 3.6 provide summaries of caseloads and FTEs for the other Trusts.

**Table 3.3**: Staff caseload and staff levels per discipline for the 6 services (B&SEHSCT)

| | **YPC Caseload: 392** | **PMHT Caseload: 50** | **CFC Caseload: 391** | **DAMHS Caseload: 43** | **EDYS Caseload 75** | **CAIT Caseload: 55** |
|---|---|---|---|---|---|---|
| Nursing | 3.6 | 2 | 1.4 | | 3.2 | 6 |
| Psychology | 1.6 (incl. 1 Consultant Grade) | | 2.6 (incl. 1 Consultant Grade) | | | |
| Psychiatry | 2.3 (Consultant Grade) | | 7.3 (incl. 5 Consultant Grade) | 1 (Consultant Grade) | 0.1 | 0.8 (Consultant Grade) |
| Social work | 6 | 3 | 2 | 2 | | 4 |
| Systemic/ family psycho-therapy | 0.3 | | 1 | | 0.3 | Staff Grade 0.8 |
| OT | | 2 | | | | 1 |
| Other | | Health Visitor 1 | | | Dietician = 1 | Healthcare worker 1 |
| **Total FTE** | **13.8** | **8** | **14.3** | **3** | **4.6** | **13.6** |
| **Staff-patient ratio** | **1:29** | **1:6 (new team)** | **1:27** | **1:14** | **1:16** | **1:4** |

### *Belfast HSCT and South East Sector Caseload*

Table 3.4, below, provides a summary of respondents' indications of the number of caseloads currently open, the total clinical staff (FTE), and the staff/patient ratios for the 6 teams within the Belfast Trust and South East Sector. It is important to note that the data on each of the six teams relate to their caseloads at the end of 2014. It is likely that these figures have changed, but comparison across teams and Trusts can be made. The teams with the largest caseloads in the Belfast HSC Trust are Tier 3 services, the YPC and the CFC, both of which had almost 400 open cases at the end of 2014. The YPC took 973 referrals in that year and the CFC accepted 668 referrals (Tables 3.3 and 3.4).

The overall staffing for the Trust was 57.1 whole time equivalent health and social care professionals, comprising of nursing staff (16.2), social work (17), psychology (4.2), psychiatry (11.5), occupational therapy (3), systemic psychotherapy/family therapy (2.4), health visitor (1), dietician (1), and health care worker (1).

**Table 3.4**: Indications of caseload, number of referred cases, the number of cases currently open (in end 2014), FTE, and estimated staff/patient ratio by team (B&SEHSCT)

| Trust | Team name | No. Referred | No. Open | Staffing (FTE) | Staff/patient ratio |
|---|---|---|---|---|---|
| Belfast | YPC Step 3 | 973 | 392 | 13.6 | 1:29 |
| Belfast | PMHT | New team | 50 | 8 | 1:6 |
| Belfast | CFC | 668 | 391 | 14.3 | 1:27 |
| Belfast &SE | DAMHS | 95 | 43 | 3 | 1:14 |
| Belfast &SE | EDYS | 81 | 75 | 4.6 | 1:16 |
| Belfast &SE | CAIT | 907 | 55 | 13.6 | 1:4 |

The overall staff-patient ratio for the Belfast & Southern Sector, based on the total number of equivalent full time staff (57.1) by open cases (1006), was 1 member of staff per 17 patients (see Table 3.6). The ratio is highest for the CAIT service (1:4) and the new PMHT (1:6), with the YPC Step 2 and CFC working to 1 FTE clinical staff member to every 29 and 27 patients respectively (Table 3.4).

**Table 3.5**: Caseload and FTE staffing (per discipline) for each Trust (except Belfast)

| **Discipline** | **SEHSCT Trust caseload=882** | | **SHSCT Trust caseload=819** | | | **NHSCT Trust caseload=1500** | **WHSCT Trust caseload=1151** | |
|---|---|---|---|---|---|---|---|---|
| | D&L CAMHS Team Caseload: 417 | ND&A CAMHS Team Caseload: 465 | A&D CAMHS Team caseload 297 | N&M CAMHS Team caseload 204 | C&B CAMHS Team caseload 318 | CAMHS caseload: 1500 (Trust) | Northern Sector CAMHS Caseload NA | Southern Sector CAMHS Caseload NA |
| Nursing | 2 | 2 | 1 | 2.4 | 5 | 10.9 | 6.8 | 5 |
| Psychology | 1.3 | 2.5 (incl.1 Consultant) | 1.4 (incl. 0.8 Consultant) | 0.8 | 2 | 4.8 (incl. 1.6 Consultant) | 2.5 (incl. 0.5 Consultant) | 2 |
| Social work | 0.5 | 3 | 1 | 0.8 | 3 | 5.5 | 7.2 | 8 |
| Psychiatry | 4.1 (incl. 1.8 Consultant) | 5 (incl. 2.5 Consultant) | 2 (incl. 1 Consultant) | 1.7 | 1.1 (incl. 0.5 Consultant) | 5 Consultant Grades 3 trainees | 2 | 3.5 (incl 2 Consultant Grade) |
| Systemic psycho therapy/Family therapy | 1.8 | 1 | 0.6 | 0.8 | | 1 | | |
| Psycho-dynamic Psychotherapy | 1 | | | | | 0.6 | | |
| Child Mental Health Practitioner | 3.5 | 4 | | | | 7 | 3.6 | 3 |
| OT | 0.5 | 1 | 0.33 | | 0.3 | 1 | | |
| Drug & alcohol worker | | | | | 1 | 1 | | |
| Eating disorder nurse | | | | | | 2 | | |
| Crisis Resolution Home Treatment Team Worker | | | | | | 6 | | |
| Medical Director/Manager | Medical Director 0.4 | | Clinic Manager 1 | | Clinic Manager 1 | | Team manager 1 | |
| Other | | | Senior MH practitioner 1 | | | Dietician 0.7 | MH practitioner 1 | |
| FTE staff (per team) | 15.1 | 18.5 | 8.33 | 6.5 | 13.4 | 48.5 (Trust) | 25.3 | 21.5 |
| **FTE staff (per `Trust)** | **33.6** | | **28.23** | | | **48.5** | **46.8** | |

### *SEHSCT Caseload*

Two local CAMHS clinics in Newtownards and Lisburn cover the South Eastern districts of North Down and Ards (ND&A) District, and Down and Lisburn (D&L) District respectively. Table 3.5, above, provides a summary of the caseload and staffing levels for the each team.

For the year 2013/2014, the total caseload across the three sectors for Tier 3 CAMHS in the SEHSCT was 882. The two local CAMHS teams in the SEHSCT reported receiving approximately 1300 referrals in the year ending 2014, with the total number of open cases standing at 882.

The overall FTE for the SEHSCT was 33.6 (Table 3.6). The overall staff patient ratio for the SEHSCT, based on the 882 open cases and 33.6 FTE staff, was 1:26.

The staff-patient ratio for both teams is reported in Table 3.6. The ratio for the Down and Lisburn Team (which was recruiting additional staff at the time they completed the mapping tool) was 1.25, and the ratio for the North Down and Ards was 1.27.

### *SHSCT Caseload*

For the year 2013/2014, the total caseload across the three sectors for Tier 3 CAMHS in the SHSCT was reported as 819 (Table 3.5). The total number of cases referred across the Trust in that time period was 2086 (269 referred in A&D; 366 step 3 & 4 in C&B; and 453 crisis referrals). Overall, the FTE for the SHSCT was 28.23.

### *NHSCT Caseload*

The number of full time equivalent staff in the Northern Trust was 48.5 (including three trainee psychiatrists). The caseload across the three teams in the Northern Trust was reported to be 1500 at any one time, with a number of cases 'co-worked.' Based on the 790 open cases, and 48.5 FTE, the staff patio ratio for the NHSCT was 1:30. The number of cases referred in the year ending 2014 was reported as 1260 with 62% of these accepted.

### *WHSCT Caseload*

The caseload across the two sectors in the WHSCT was reported to be 1151 at the end of 2015. The number of cases referred in the year 2014/15 was reported as 1843.

The two sectors have 48.6 FTE staff employed in the two services. While the staffing levels were presented across two teams, the caseload was presented as a total so the staff ratio is by Trust as opposed to team (see Table 3.6). Based on the 1151 open cases, and 48.6 FTE, the staff patio ratio for the WHSCT was 1:25.

**Table 3.6**: Indications of caseload, number of referred cases, the number of cases currently open (end 2014), FTE, and estimated staff/patient ratio BY team (all trusts except Belfast)

| Trust | Team name | No. Referred | No. Open | Total clinical staff (FTE) | Staff/patient ratio [8] |
|---|---|---|---|---|---|
| BHSCT | All 6 teams | 2724 | 1006 | 57.1 | 1:17 |
| SEHSCT | D&L | 692 | 417 | 18.5 | 1:25 |
| | ND&A including primary care – steps 2 and 3 | 601 | 465 | 15.1 | 1:27 |
| | Total SEHSCT | 1293 | 882 | 33.6 | 1:26 |
| SHSCT | A&D | 269 | 297 | 8.33 | 1:36 |
| | N & M | - | 204 | 6.5 | 1:31 |
| | C&B | 366 step 3&4 453 crisis places | 300 step 3&4 18 crisis places | 13.4 | 1:24 |
| | Total SHSCT | 2086 | 819 | 28.23 | 1:29 |
| NHSCT | All 3 teams | 1260 | 790 | 48.5 | 1:30 |
| WHSCT | Both sectors (Northern and Southern) | 1843 | 1151 | 46.8 | 1:25 |
| **Total by Region** | | **9206** | **4618** | **214.23** | **1:22** |

### *3.4.3 Referrals and Transfer of Responsibility*

Each CAMHS team was also asked to indicate how many cases they considered suitable for transfer to adult services per year over the past three years (*potential referrals*), as well as the number of cases that actually made the transition from their service to adult services per year (*referrals accepted*).

#### *BHSCT Referrals*

A summary of referral estimates for the Belfast Trust is presented in Figure 3.3 below. In this Trust, Step 3 services at the YPC make the majority of referrals to adult services (an average of 34 per year over the previous three years), from which approximately three quarters (n=26) per year were accepted.

[8] The staff-patient ratio is based on the total number of equivalent full time staff by open cases.

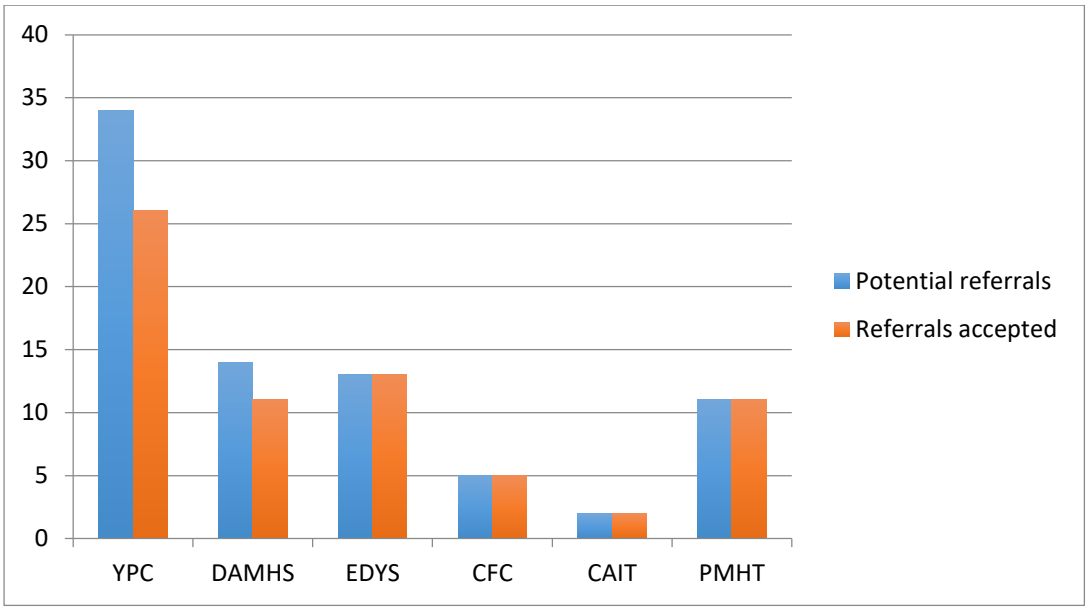



**Figure 3.3**: Estimated average number of potential referrals and referrals accepted from service to adult service per year (estimate over the last 3 years) Belfast Trust

### *SEHSCT Referrals*

With regard to the number of potential and accepted referrals per year over the previous three years, the ND&A team estimated that 62 young people were referred in the previous year with one third accepted. Statistics were not available beyond that year. Accurate records of referrals were not available for D&L, but an estimate of less than 100 was given. It was noted, in relation to the question on the number of referrals accepted by adult services that *'more work is required in recording outcomes.'*

### *SHSCT Referrals*

Participants were asked to indicate how many cases they consider to be suitable for transfer to adult services per year (potential referrals) as well as the number of cases that actually make the transition from their service to adult services per year (referrals accepted). None of the three respondents from the SHSCT had this information available to them.

### *NHSCT Referrals*

The Northern Trust stated they were unable to provide exact statistics for the number of cases suitable for transfer to adult services per year (potential referrals) as well as the number of cases that actually make the transition from their service to adult services per year (referrals accepted). It was estimated that 30-50 potential referrals per year were made across the whole service, and that 30-50 referrals were accepted, 'i.e. *100% acceptance or as near* as'.

### *WHSCT Referrals*

The CAMHS teams in the WHSCT estimated that between 60 to 80 cases were considered suitable for transfer to adult services across the Trust per year. The number of referrals accepted per year, over the last three years, was given as 50, that being the number of 'potential cases' named at transition meetings.

### *3.5.4 Transfer of responsibility*

In order to explore how the transfer is managed, each team was asked to indicate whether they retained or transferred the lead for the care of the young person at transition. Table 3.7, below, provides a summary of the links CAMHS teams had with both statutory and community services.

### *Belfast HSCT Transfer of responsibility*

Each team was asked to indicate the nature of the links they had with both statutory and community services at transfer, whether they retained the lead for the care of the young person, or whether they transferred lead responsibility to the other organisation or service. Table 3.7, demonstrates, that on the whole, the teams transfer the lead responsibility to other services at the point of transfer. The exception to this is the DAMH service, which retains the lead for links they make with Social Service (SS), Criminal Youth Justice (CYJ) and Educational services (ES).

**Table 3.7:** Summary of the transfer lead (BHSCT)

| | Transfer patient to: | | | | | | | | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | CMHTS | | Eating Disorders | | Educational | | Disability Learning | | Psycho-therapy | | Primary Care | | Forensic Sciences | | Addiction | | Justice Criminal | | Services Social | | Other | |
| | RL | TL | RL | TL | RL | TL | RL | TL | RL | TL | RL | TL | RL | TL | RL | TL | RL | TL | RL | TL | RL | TL |
| YPC | | X | | X | | X | | X | | X | | X | | X | | X | | | | | X | X |
| DAMH | | | | | X | | | | | X | | X | X | | | X | X | X | X | X | X | X |
| EDYS | | | | X | | | | | | | | X | | | | | | | | | | |
| CFC | | X | | X | | X | | X | | X | | X | | X | | X | | X | | X | | |
| CAIT | | X | | X | | X | | X | | X | | X | | X | | X | | X | | X | | |
| PMHT | | X | | X | | X | | X | | X | | X | | X | | X | | X | | X | | |

**RL** – Retain Lead (CAMHS team retain the lead responsibility for patient care.
**TL** – Transfer Lead (Adult service takes lead responsibility)

### *South Eastern HSCT Transfer of responsibility*

In the SEHSCT, the two CAMHS teams in the Trust transfer the lead responsibility to the other services they link with the exception of the MACS voluntary organisation where the D&L team retain the lead for the transfer cases.

### *Southern HSCT Transfer of responsibility*

The three teams in the SHSCT Trust were asked to list the statutory adult teams and community and voluntary organisation with which they work, and to indicate whether they transfer or retain the lead responsibility for cases. Table 3.8 presents the responses to this question for all Trusts (except BHSCT). In summary, the Armagh and Dungannon team indicated that they do not retain the lead for cases they work on with adult services, and provide the following additional notes:

> *On very few occasions where child / young person was accepted by CAMHS but later noted as being best served by Learning Disability services*
>
> *On very exceptional circumstances CAMHS works with AMHS whilst retaining lead (for example where a young person is placed into Adult In-Patient Unit or where adult home treatment team are involved).*
>
> *As transfer occurs, CAMHS retain lead responsibility until other services confirm appointment for young person.*

> *All transfers to AMHS are sent to Adult Central Booking system. Following screening, they are prioritised and directed to best services.*
>
> *Where a child or young person is admitted to Beechcroft regional inpatient centre, an in-patient Consultant Psychiatrist provides case lead. Community CAMHS remains actively involved.*

The same team stated that they link with a range of community and voluntary services, that they *'signpost'* parents and young people to these services, and that:

> *CAMHS retain case responsibility on all cases accepted and opened to them. There are a few services which the Trust have formal contractual arrangements with such as Family Trauma Centre, NOVA project, NSPCC, Bernardo's Projects, and CAMHS refer cases, and if accepted by such services, case responsibility may be transferred or not depending on individual case presentation / needs.*

The Newry and Mourne Team gave two statements in relation to this question. On working with adult teams they said that they:

> *Begin processes of transfer normally at 17 years and 6 months unless young person arrives in crisis before 18th birthday. In that case transfer processes begin but CAMHS holds case until young person seen in AMHS.*

And in relation to links with the community and voluntary services:

> *CAMHS links with a range of community and voluntary sector (listed, see table).*
>
> *CAMHS closes all cases at 18.*

Craigavon and Banbridge elaborated on the relationship they have with some of the community and voluntary organisations, to the effect that *'some of the cases remain open to CAMHS until engaged with the C&V sector.'*

### *Northern HSCT Transfer of responsibility*

The Northern HSCT Teams had links with both statutory and community services and the three CAMHS teams both transfer and retain the lead responsibility when linking with other statutory and community services.

### *Western HSCT Transfer of responsibility*

The CAMHS teams in the Western Trust generally transfer the lead to statutory organisations they link with, the exception being Criminal Justice and Social Services, where the CAMHS team retain the lead. The Northern Sector team identified a number of community and voluntary organisations they link with, the majority of which they transfer the lead to. They both retain and transfer the lead to YouthLife and Daisy.

**Table 3.8**: Summary of transfer lead for all Trusts (exception BHSCT)

| | | CMHTS | | Eating Disorders | | Educational | | Learning Disability | | Psycho-therapy | | Primary Care | | Forensic Sciences | | Addiction | | Criminal Justice | | Social Services | | Other | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | RL | TL | RL | TL | RL | TL | RL | TL | RL | TL | RL | TL | RL | TL | RL | TL | RL | TL | RL | TL | RL | TL |
| South Eastern HSC | D&L | | X | | X | | | | | | X | | | | | | X | | | | | | |
| | NDA | | X | | X | | | | | | X | | | | | | X | | | | | | |
| Northern HSC | NHSCT | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | | |
| Southern HSC | A&D | | | | X | | | | | | | | | | | | | | | | | | |
| | C&B | X | X | | | | | | | | | | | | | | | | | | | X | X |
| | N&M | | | | | | | | | | | | | | | | | | | | | | |
| Western HSC | WHSCT | | X | | X | | | | X | | X | | X | | X | | X | X | | X | | X | X |

**RL**= Retain Lead (CAMHS team retain the lead responsibility for patient care.

**TL** =Transfer Lead (Adult service takes lead responsibility)

### *3.4.6 Transition Age Boundaries*

All teams were asked to describe the transition criteria.

### *BHSCT Transition age boundaries*

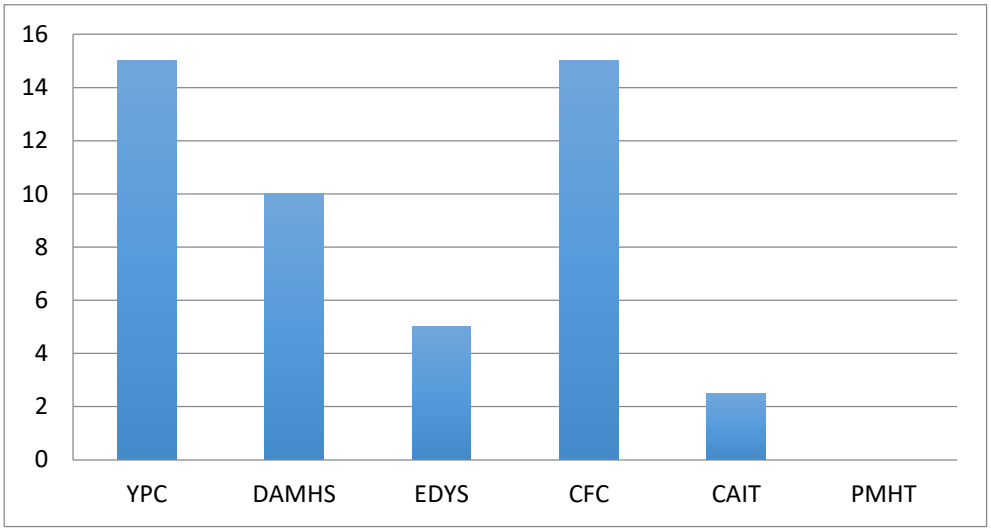
Eighteen years is the transition boundary for all CAMHS teams in the BHSCT. However, the DAMHS and YPC teams indicated that in some circumstances care may be extended beyond the age of 18:

> *We are a CAMHS under eighteen team; we would ensure to the best of our ability, that the most appropriate team we have referred the young person to, has had a comprehensive handover face-to-face introduction and have had their first meeting before we discharge. If a special case can be made of not referring on because of the possibility of a few more sessions may allow no transition to occur, we may consider keeping until over eighteen*. [DAMHS Team]

> *No exact figures available but if therapy is felt to be able to be completed in 3-6 months with no further MH input required, case will be discussed at Transition panel with adult teams and small numbers will remain in CAMHS and discharged at completion of treatment back to GP. Usually between 10-20 per year*. [YPC Team]

Respondents were asked to indicate the number of patients staying within their service after crossing the transition boundary per year (estimate over the last three years). Figure 3.4, below, provides a summary for the Belfast and South East Health and Social Care Trust areas.

**Figure 3.4**: Estimated number of patients staying within their service after crossing the transition age boundary per year (estimate over the last three years) B&SEHSCT




### *SEHSCT Transition age boundaries*

Transition to adult services in the SEHSCT is defined by age, namely eighteen years. North Down and Ards indicated that 15 young people remained within CAMHS past their 18th birthday over the previous three years. In Down and Lisburn, this information was not available but the respondent indicated that *'some flexibility'* is applied in the service though care is usually not extended for more than six months.

### *NHSCT Transition age boundaries*

The respondent from the Northern Trust indicated that the transition boundary between their service and adult services was dictated by age, which was 18 years. For this Trust, there was no response to the item asking for the number of patients who stayed within the service after crossing the transition boundary, but this information was made available during case note review (reported in Chapter 4), and was given as 69 remaining with CAMHS beyond the age of 18 years of age between 2010 and 2014. North Down and Ards indicated that 15 young people remained within CAMHS past their 18th birthday over the previous three years. In Down and Lisburn, this information was not available but the respondent indicated that *'some flexibility'* is applied in the service though care is usually not extended for more than six months.

### *WHSCT Transition age boundaries*

Similar to the other Trusts, the transition boundary in the WHSCT is eighteen years. That said, on average, each year approximately twenty young people (mostly with a diagnosis of ADHD) per year remain within the service beyond eighteen. It was noted that the lack of provision for those with ADHD in adult services has meant that CAMHS have to retain these

young people if they are on medication. It was also noted that at the time of completing the mapping tool, training was being provided to AMHS personnel in relation to ADHD.

### *3.4.7 Transition Protocols and Process (All Trusts)*

In order to gain an insight into the transition process involved in each of the Trust, respondents were asked to describe protocols and processes involved in the transition. During the mapping survey, each Trust was asked if they undertake any of these 6 transition practices:

1. Documented hand-over planning
2. Joint meeting with adult services
3. Involvement of the parent/carer in care plan and decision making
4. Involvement of the service users in care plan and decision making
5. Preparing the young person for ending one therapeutic relationship and starting another
6. Accountability for the process (e.g. a single clinician may be identified from one of the services to co-ordinate the transition)

Each Trust response to this question is summarised in Table 3.9.

**Table 3.9**: Transition Process for each Trust

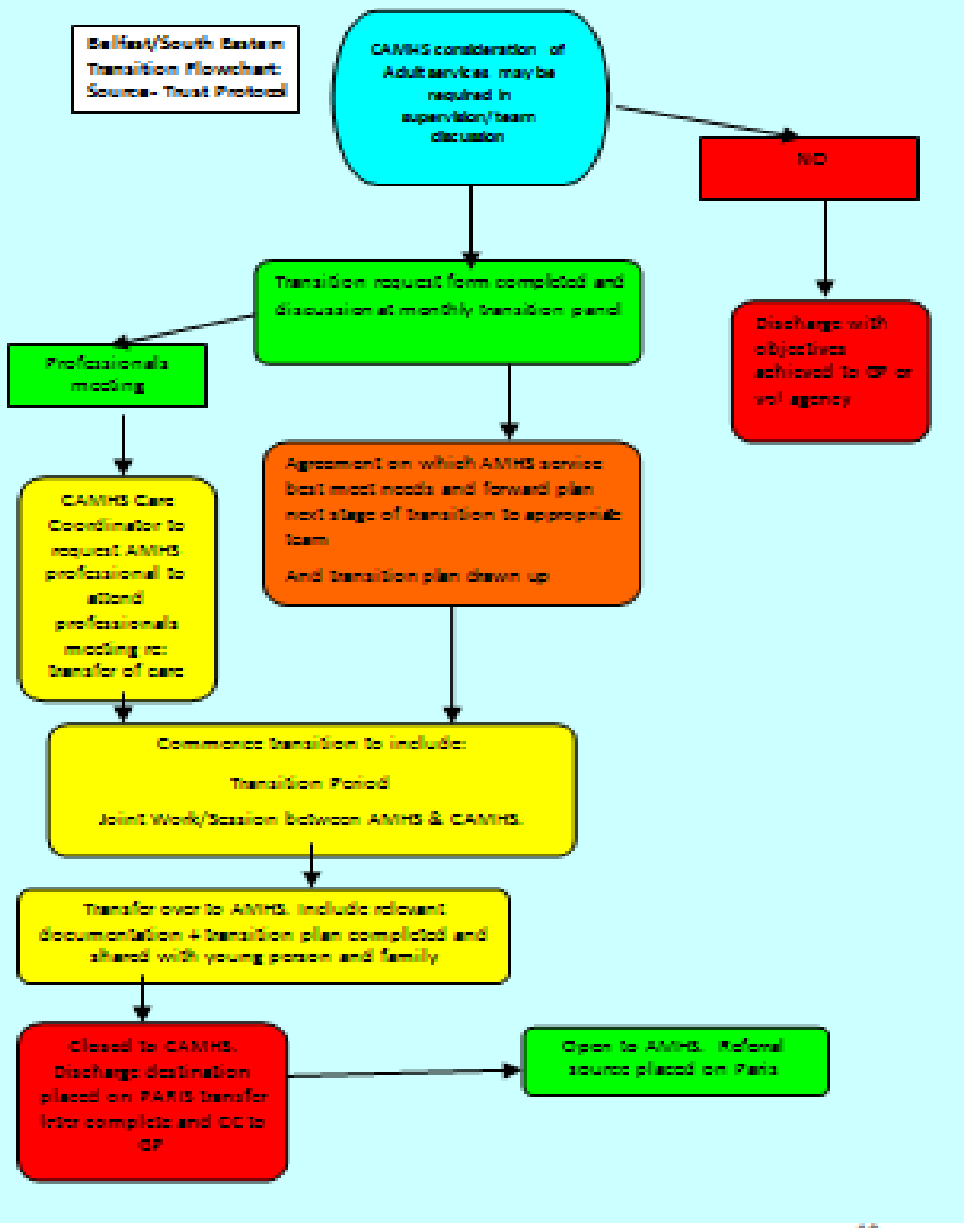
| | BHSCT | NHSCT | SEHSCT | | SHSCT | | | WHSCT |
|---|---|---|---|---|---|---|---|---|
| **Process Action** | All | All | NDA | D&L | N&M | A&D | C&B | North & South |
| *Documented hand-over planning* | A | A | A | A | S | S | A | A |
| *Joint meeting with adult services* | A | S | A | A | S | S | A | A |
| *Involvement of parent/carer in care plan & decision making* | A | A | A | A | S | A | A | A |
| *Involvement of the SU in care plan and decision making* | A | A | A | A | S | A | A | A |
| *Preparing the young person for ending one therapeutic relationship and starting another* | A | A | A | S | S | A | A | A |
| *Accountability for the process (e.g. single clinician to coordinate the transition)* | A | A | A | S | A | A | A | A |

Code: A Always S Sometimes

### *BHSCT Transition Process*

With regard to the transitions process, as summarised in Table 3.9, above, all six teams in the BHSCT who completed the mapping survey indicated that each of the 6 transition tasks were always followed. A flow chart of the BHSCT transition protocol, which is also used by the SEHSCT, is provided in Figure 3.5

**Figure 3.5**. Flow chart summarising BHSCT and SEHSCT Transition Protocol.




The content of this protocol is analysed alongside protocols from the other four HSC Trusts later in the chapter.

The teams were asked to elaborate on how they undertake the transition process. Five of the six team-leads in the Belfast Trust provided the following answer:

> *A transition referral form is completed prior to a young person's 18th birthday. The young person and their family are involved in the care plan and decision-making regarding transition. A transition panel meets on the second Monday of every month. The keyworker presents the case and this is discussed amongst the group. The appropriate Adult Services will agree to take the case, the transition referral form and FACE risk are given to them and a joint meeting is arranged. The young person is prepared for this transition and supported throughout. The keyworker(s) are accountable for this process and help to coordinate the transition.* [CAMHS, Belfast]

The protocol for the transition of young people from the YPC team to the Early Intervention Team (EIT) is summarised within the CAMHS and AMHS Transition Protocol. The YPC and EIT teams hold their own transition meetings once a month specifically aimed at assessing transitions for young people with a psychotic disorder. The transition process is started up to one year before the young person is due to turn 18. In the six months prior to transfer a formal referral is agreed. Clinicians from the EIT attend joint appointments with the young person and their CAMHS key-worker. A transfer-planning meeting is arranged one month prior to the transition and an appointment with the EIT follows this. The young person is named at the Belfast Transition Panel for the records.

### *SEHSCT Transition Process*

As noted above, the transition protocol used by the SEHSCT is the same as BHSCT Transition Protocol with some local variations. The protocol and transition process was under review in the SE Trust at the time the mapping tool was completed. The two SEHSCT teams indicated the elements which 'always', 'sometimes' or 'never' formed part of their transition process (see Table 3.9). While all of the items listed *'always'* formed part of the process in North Down and Ards, the Down and Lisburn team noted that preparation for the end of the therapeutic relationship was only undertaken 'sometimes' and that *'more audit is required to verify'* some of the processes. Both teams indicated that a written policy/guideline for managing the interface was *'in progress'.* The ND&A team elaborated on the transition process with the following statement:

> *Written referral to adult mental health requesting a transfer meeting, with family and young person's consent, keeping them appraised of process throughout, preparing for transition and acknowledging the challenges this can bring with young people and family, whilst being mindful that transitions can be times of increased risk in mental health settings, and undertaking on-going risk assessment and risk management. Work is on-going regarding SET transition panel.* (North Down & Ards Team)

### *SHSCT Transition Process*

All three of the respondents from the various teams in the SHSCT indicated that the six procedures, listed above (Table 3.9), were either *sometimes* or *always* part of the transition process.

C&B Respondents were asked to elaborate on how they carry out the above transition process. One of the respondents left this item blank, while the other two provided the following responses:

> *When it is thought that a young person requires a transition to adult services this is discussed with the young person and their parent or guardian. Consent is gained and the Key Worker makes a referral to Adult Psychiatry and a FACE Risk Profile is attached to the referral. A decision is made as to whether the young person requires a referral to Support and Recovery or to Primary Care and the young person and the family member is updated on the process. On occasions in more complex cases the young person may be accompanied to their first appointment with Adult Services or Adult Services on occasion has joint the CAMHS Key Worker.*

> *It is normally straightforward, however if the young person comes into a service late – i.e. in crisis just prior to 18 – the transfer process to adult mental health may take longer. AMHS have a waiting list from 9-13 weeks. Also the CAMHS worker may not know who the person is allocated to and go to the transfer meeting with no named worker. The information is fed into a primary care team worker, but the named keyworker not identified. All the documents are forwarded and then the keyworker in adult will make contact with CAMHS worker once they are identified as assuming case. Sometimes this is straightforward and sometimes not.*

The Transition Pathways for young people leaving CAMHS are detailed in the diagrams below. These form part of the SHSCT's Transition Protocol (updated in 2015) (see Appendix 5). All referrals to adult service are made through a central Booking Centre and triaged.

### *NHSCT Transition Process*

As part of the transition process in the Northern Trust, the Clinical lead indicated that most procedures listed in Table 3.9 '*always'* happened, but that joint meetings with adult services only '*sometimes*' happen. It was also stated that a closure policy was in place, as were written policy guidelines for managing the interface with adult services. A Transition Protocol was provided, the content of which is described later in the chapter. Respondents were asked to elaborate on how they carry out the above transition process. The respondent from the Northern Trust provided the following response:

> *We aim to involve the young people in decisions regarding transition and to respect their views; many young people express a desire to remain with their CAMHS therapist. Though we have a structured transitioning protocol (enclosed) we try to be flexible and manage the transition as sensitively as we can.* (Northern HSCT)

### *WHSCT Transition Process*

The Team Manager from the WHSCT indicated that all the procedures tasks listed in Table 3.9 'always' happened. The documented hand-over included *'minutes and outcome discussed.'* The respondent expanded on the process of joint meetings with adult services indicating that these meetings were *'not always face to face, could be telelink.'* While service user involvement in the decision-making, was recorded as *always* happening as part of the process, it was noted that this was *'not always as clear as it could be in terms of their understanding of the decision and what it means for them.'* A transition protocol was also provided, and the guidelines for managing the interface were *'written within the Transition Protocol'*. Whilst there was no written Closure Policy, the CAMHS team *'will sometimes arrange to meet adult services depending on the case. (They) will follow an agreed closure practice, but (this is) not always written in policy. A discharge letter will always be sent to the GP.* (CAMHS WHSCT)

The Transition Protocol between CAMHS and adult services in the WHSCT is provided in Appendix 6.

### *3.4.8 Content Analysis of Transition Protocols*

There is no regional policy or protocol with regard to the transition of young people from CAMHS to AMHS in Northern Ireland. Each of the five HSCTs has developed their own protocol. The BHSCT and the SEHSCT share the same protocol with local variations. The WHSCT includes a separate section on the transition of young people with ASD to adult services, and the BHSCT and SEHSCT protocols include specific guidelines for those making the transition from local CAMHS to the Early Intervention Team (EIT).

A content analysis of all five protocols submitted to the project was undertaken, and five main themes identified. These themes addressed the:

- Boundaries and criteria for transition (items 1-6)
- Involvement of young people (& carers) in decision making about transition (7-8)
- Nature of joint working between CAMHS & AMHS around transition (items 9-10)
- Referral process, the nature of communication and exchange of information between services (items 11-14)
- Procedures for transfer of care, including transfer of documentation (items 15-18)

#### *The boundaries and criteria for transition*

The transition boundary between CAMHS and AMHS was defined by age in all five protocols, and set at eighteen years. Some flexibility with regard to the age of transition was inferred in the wording of two of the protocols, the NHSCT and WHSCT. Full transfer of care at eighteen

years was presupposed in the NHSCT protocol *'unless clinically indicated otherwise,'* and the WHSCT stated that the protocol is *'for young people aged 18 and over.'* The other three Trusts describe circumstances when a referral/transfer can be made to adult services before a person's 18th birthday: namely if a new referral is received by CAMHS nine to twelve weeks before the person is eighteen it can be passed on directly to AMHS.

In all but the SHSCT, a referral is made to adult services six months before the person's 18th birthday. Both the WHSCT and SHSCT advise that this is made earlier in complex cases. The SHSCT typically refers to adult services when a young person is aged 17 ¾ years old. The NHSCT, SEHSCT and BHSCT outline the circumstances when care can be extended in CAMHS beyond the age of eighteen. These include the situation where the young person is acutely unwell, or it is anticipated that an intervention can be concluded (Belfast and South Eastern) or where it is *'clinically indicated'* that CAMHS should continue working as agreed between both services (NHSCT).

Three of the protocols suggest that the numbers requiring transfer to AMHS are, typically, small. The expected criteria for those who do require continued support from statutory mental health services are listed in all but one of the protocols (SHSCT). 'Mental health illnesses', 'psychiatric disorders' are named as likely criteria. 'Mental health problems' likely to continue into adulthood, or those expected to need long-term support were also identified as possibly meeting the criteria for transition. Three Trusts identified young people with a diagnosis of ADHD as meeting the criteria for transition, and one named young people with ASD.

### *The involvement of young people in decision making about transition*

All five protocols state that the young person and carer/family should be involved in the discussion and decisions about transition to adult services, or the need to transfer. Three specifically state that the permission of the young person should be sought before a referral is made (NHSCT, BEHSCT, and SEHSCT) and the SHSCT states that information should be provided to the young person and parents/carers prior to referral. The Western Trust does not specify a requirement for the consent of young person/carer in order to make a referral.

### *The nature of joint working between CAMHS & AMHS around transition (items 9-10)*

A joint meeting with the young person, carers if appropriate, and their CAMHS and AMHS key-workers is recommended in all protocols. The WHSCT's protocol states that any joint working needed will be discussed at a joint care-planning meeting between key personnel from both services. The young person and their family may be involved in this meeting if appropriate.

The BHSCT and SEHSCT protocols suggest that a period of joint working in line with Promoting Quality Care will follow an agreed referral to adult services. Joint working is not

specifically named in the NHSCT protocol or in the SHSCT, and is recommended if needed in the WHSCT protocol.

### *The referral process, the nature of communication and exchange of information between services*

In both the WHSCT and SHSCT a telephone call is suggested as the initial contact between a CAMHS key-worker and adult services to discuss a possible transition case. The Northern Trust Protocol states that a referral should be made by CAMHS key-worker to AMHS six months before the young person's 18th birthday and that the Adult services named worker will subsequently initiate a face to face meeting with CAMHS worker to discuss. Initial contact between services in the BHSCT and SEHSCT is the Transition Panel. The detail of what constitutes a referral varies across protocols. A template referral form is attached to the BHSCT and SEHSCT protocol; it includes the reason for referral and diagnosis, psychiatric history, medication history, family history, involvement with other agencies and current mental state, as well as the FACE Risk Assessment. The summary of work completed in CAMHS, diagnosis, and risk assessment are part of the referral process in the Northern Trust Protocol. The SHSCT protocol suggests that similar detail is transferred to AMHS but do not specify that this is part of an actual referral form. While the WHSCT protocol indicates that a referral form or letter is sent to adult services, the content of this is not specified.

Transition panels are part of the transition process in the WHSCT, BHSCT and SEHSCT; a CAMHS multidisciplinary team meeting is part of the SHSCT process, while a 'transfer meeting' is named as part of the process in the NHSCT but the structure of this meeting is not clear from the protocol.

### *The procedures for transfer of care, including transfer of documentation*

The specifics of how the transfer of care from CAMHS to AMHS happens are variously described in the protocols. All make provision for a meeting between CAMHS and AMHS key staff, which may involve the young person and, if appropriate, the carer. In the SHSCT the presentation of the case is made at the adult clinical team meeting. The AMHS key-worker subsequently attends meetings as requested by CAMHS to ensure the smooth transition.

There is some anomaly in the protocols around the transfer of patient charts from CAMHS to AMHS. There is no specific mention of the transfer of charts in the BHSCT and SEHSCT's Protocols, although they do state that '*the handover of all appropriate information and documentation*' will take place at CAMHS / AMHS professional meetings. The SHSCT allow for the transfer of patient charts with the consent of the service user. The WHSCT state that case files will be transferred but do not mention consent, and the NHSCT include a section in their Protocol on Information Sharing, and a confirmation that 'personal information relating to patients can be shared between CAMHS and AMHS, even without consent.' All of the

protocols, other than the NHSCT protocol, determine that a discharge letter is circulated to all relevant parties including GP, adult team, and for BHSCT and SEHSCT to the young person and, where appropriate, the family.

Table 3.10 summarises the other information included in the protocols. Only three include a reference to how other sources of help, such as community and voluntary organisations may be involved in the transition process.

**Table 3.10** Summary of protocols and policies guiding transition from CAMHS for each Trust

| Content in Protocol | BHSCT | SEHSCT | | SHSCT | NHSCT | WHSCT |
|---|---|---|---|---|---|---|
| **Transition Boundary** | 18 | 18 | | 18 | 18 | 18 |
| **Flexibility in age of transfer** | If nearing 18th birthday when referred to CAMHS, discuss with AMHS. If turns 18 within 9 weeks of referral, it is forwarded to AMHS Central Point of Referral. | If nearing 18th birthday when referred to CAMHS, discuss with AMHS. If turns 18 within 9 weeks of referral, it is forwarded to Central Point of Referral. | | Can refer at 17 ¾ if referral made to CAMHS at that age. | Not specified, though states the protocol presupposes full transfer at 18 unless clinically indicated otherwise | Not specified; though protocol is for 'YP aged 18 and over' |
| **Timing of referral** | 6 months before transfer date | 6 months before transfer date | | 17 ¾ complex cases earlier | 17 ½ years | 17 ½ or in complex cases from 17 years |
| **Discussion with YP and Carer, CAMHS keyworker** | Yes – discussed with SU and family | Yes – discussed with SU and family | Yes - consent required to make referral. Plans agreed on basis of informed consent. | Yes- this must take place regarding the need to transfer | YP, and family (where appropriate) will be at centre of the process | |
| **Permission from YP sought to make referral** | Yes – consent of young person required to make referral to AMHS | Yes – consent of young person required to make referral to AMHS | | Yes | Yes – permission of YP will be sought | Not specified |
| **Initial contact with AMHS** | Transition panel | | | Telephone call between CAMHS, KW and AMHS Lead to arrange presentation of case at AMHS MDT meeting | F2F meeting CAMHS KW and AMHS prior to transfer meeting | Telephone call between CAMHS KW and AMHS team manager to discuss appropriate transition method |
| **Content of referral specified** | Template of Transition Referral Form included in Protocol- reason for referral; ongoing treatment required; psychiatric history; medication history; family history; family psychiatric history; social history; | Template of Transition Referral Form included in Protocol- reason for referral; ongoing treatment required; psychiatric history; medication history; family history; family psychiatric history; social history; medical history; substance history; forensic history; developmental history; education; involvement with other agencies; current mental state; FACE risk assessment. | | FACE Risk assessment<br>-Case summary<br>-Interventions and multi-agency work completed in CAMHS | -Diagnosis<br>-Rationale for transfer<br>-Risk assessment<br>-Summary of work with CAMHS<br>-Areas to be addressed in AMHS | Referral letter or form – but content not specified |

| Content in Protocol | BHSCT | SEHSCT | SHSCT | NHSCT | WHSCT |
|---|---|---|---|---|---|
| | medical history; substance history; forensic history; developmental history; education; involvement with other agencies; current mental state; FACE risk assessment. | | | | |
| **Maximum waiting period between referral and pick up with AMHS** | | | Not specified. But AMHS KW will be appointed to link with CAMHS KW within 7 days after case accepted at MDT meeting | 9 weeks | Transfer/referral not to be treated as external referral |
| **Referral process** | Referral form forwarded to Assistant Children's Service Manager to bring to the Transition Panel | Referral form forwarded to Assnt Children's Service Manager to bring to the Transition Panel | Booking Centre – point of entry for all new referrals to AMHS. All agreed transfers to make referral through booking Centre | Referral made by CAMHS worker to AMHS (procedure not specified)<br>Referral to Psychological Therapy Services will be made through CMHT | -Camhs KW contact AMHS team manager -Case presented at Panel meeting.<br>-Referral letter from CAMHS to appropriate AMHS |
| **Transition Panel (TP)** | Yes. All likely transition cases to be discussed at transition panel. Decisions on outcomes made or professional meeting arranged to discuss more complex cases.<br>Meets monthly | Yes. All likely transition cases to be discussed at transition panel.<br>Decisions on outcomes made or professional meeting arranged to discuss more complex cases.<br>Meets monthly | No panel.<br>CAMHS multidisciplinary team meeting to discuss and agree transfer of cases to AMHS | No | Yes. Names of young people considered eligible for transition sent to chair of panel for discussion.<br>Meets quarterly. |
| **Transfer meeting** | Yes, where transition is complex, a transition meeting with YP, carer and all involved in care, statutory and non-statutory services. To | Yes, where transition is complex, a transition meeting with YP, carer and all involved in care, statutory and non-statutory services. To happen 3 months before 18th birthday | CAMHS KW/Lead will attend AMHS Clinical Team Meeting and present case.<br><br>AMHS KW will attend all meetings | Yes -timing agreed jointly<br>A face to face meeting between CAMHS and AMHS staff takes place prior to this transfer meeting. | - Transfer meeting arranged following TP discussion if required. -Key staff from both services meet.<br>-Meeting may involve YP/family<br>-Meeting agrees KW worker from AMHS; date of initial assessment; date of transfer; agreement on any |

| Content in Protocol | BHSCT | SEHSCT | SHSCT | NHSCT | WHSCT |
|---|---|---|---|---|---|
| | happen 3 months before 18th birthday | | requested by CAMHS to ensure smooth transfer. | Timing of both based on clinical need. | joint working; agreement on roles and responsibilities |
| **Transfer of documentation** | Handover of all appropriate information and documentation to happen at joint meeting with CAMHS & AMHS professionals, plus young person and family for complex cases. | Handover of all appropriate information and documentation to happen at joint meeting with CAMHS & AMHS professionals, plus young person and family for complex cases. | -Up to date Mental Health Assessment<br>-FACE Risk Assessment<br>-Agreed transition plan<br>-Case summary of CAMHS involvement, with interventions and multi-agency working | Not specified | Not specified |
| **Transfer of charts** | Not specified | Not specified | With consent of Service User | CAMHS ensure safe transfer. Notes can be transferred without patient permission as per Information Governance Team | Case files will be transferred to adult service. |
| **Joint meeting with YP, CAMHS and AMHS** | Joint meeting should take place with CAMHS clinician and AMH worker, SU and family | Joint meeting should take place with CAMHS clinician and AMH worker, SU and family | Yes with SU, their carer if appropriate, and AMHS KW. Always happens for those transferring to support and recovery | Yes. With AMH KW after transfer meeting. If appropriate with a MDT also 3 months prior to 18th | If appropriate |
| **Joint Working/Parallel Care** | A period of joint working and handover in line with Promoting Quality Care | A period of joint working and handover in line with Promoting Quality Care | Once AMHS transfer agreed, CAMHS arrange meeting with YP, & carer if appropriate, to explain transfer process. Good practice that AMHS keyworker also attend. | Not specified | If agreed it is needed |
| **Extended care with CAMHS after 18** | Transfer postponed if SU is acutely unwell or if anticipated that episode of care can be concluded within a few months | Transfer postponed if SU is acutely unwell or if anticipated that episode of care can be concluded within a few months | Not specified | Yes, where clinically indicated that CAMHS should continue working. Time frame agreed between CAMHS and AMHS | Not specified |

| Content in Protocol | BHSCT | SEHSCT | SHSCT | NHSCT | WHSCT |
|---|---|---|---|---|---|
| **Criteria for consideration of transfer to AMHS** | -Psychotic Disorders (transition to EIT)<br>-YP with diagnosis of ADHD needing on-going medication.<br>-Gender Identity Disorder<br>-Eating Disorder<br>-Self Harm<br>-Drug and Alcohol Misuse with mental ill health | -Psychotic Disorders (transition to EIT)<br>-YP with diagnosis of ADHD needing on-going medication.<br>-Gender Identity Disorder<br>-Eating Disorder<br>-Self Harm<br>-Drug and Alcohol Misuse with mental ill health | Not specified | -Eating Disorder<br>-ADHD<br>-Referred after 17 to CAMHS and expected to need long term support<br>-Ongoing mental illness or disorder | -Mental health problems likely to continue into adulthood<br>-Psychiatric or evolving psychiatric illness – ICD 10 psychiatric diagnosis requiring specific intervention provided by AMHS<br>-Severe psychological difficulties<br>-YP with ASD |
| **Discharge procedure from CAMHS** | Yes. Discharge letter copied to GP, Adult team, YP and family where appropriate. Discharge destination entered on database | Yes. Discharge letter copied to GP, Adult team, YP and family where appropriate. Discharge destination entered on database | Yes. Discharge letter to GP and cc'd to AMHS KW | Not specified | Discharge letter circulated to all involved |
| **Other sources of help identified or to be considered** | Yes. Community and voluntary sector. Advocacy offered to SU. Support from CAUSE for carers. | Yes. Community and voluntary sector. Advocacy offered to SU. Support from CAUSE for carers. | Refer back to GP | Not identified | Adult services advise on alternative sources of help where AMHS is not appropriate |
| **Underpinned by policies and principles** | Identifies Top Ten Principles for Transition from SCIE Fair Access to Services Paper 10<br>Lists 8 Principles for BHSCT CAMHS transfer to AMHS. Advocate a period of joint working in line with Promoting Quality Care | Identifies Top Ten Principles for Transition from SCIE Fair Access to Services Paper 10<br>Lists 8 Principles for BHSCT South East Sector CAMHS transfer to AMHS | Identifies 8 principles underpinning delivery of service in SHSCT | Not identified | Underpinned by service policies and principles of CAMHS and AMHS |
| **Protocol drawn up by** | Not specified | Not specified | HOS; CAMHS Psychiatrist; AMHS practitioners from Primary Mental Health; Support and | Not specified | Not specified |

| Content in Protocol | BHSCT | SEHSCT | SHSCT | NHSCT | WHSCT |
|---|---|---|---|---|---|
| | | | Recovery; Acute Services | | |
| **Other Info** | Refers to SCIE principles.<br>Identifies 8 Principles for Belfast Trust CAMHS transfer to AMHS.<br>Separate Protocol in place for transition between CAMHS and EIT<br>Procedure for yp turning 18 whilst in inpatient.<br>Appendix- Referral Form | Refers to SCIE principles.<br>Identifies 8 Principles for Belfast Trust CAMHS transfer to AMHS.<br>Separate Protocol in place for transition between CAMHS and EIT<br>Procedure for yp turning 18 whilst in inpatient.<br>Appendix- Referral Form | Makes distinction between transition and transfer.<br>Transition overseen by clinic manager.<br>Roles and responsibilities defined of all involved in process.<br>Transition pathway outlined for: new urgent referrals from GP for those aged 17 and 9 months or more; new routine referrals for same group; referrals from professionals other than GPs; emergency liaison referrals<br>Appendix – Transition Plan form | Appendix includes Information sharing and data protection act 1988 | Addresses the specific transition of young people with ASD to adult services as taking one of three routes: if yp has co-occurring ASD and learning disability WHSCT Children's Disability Protocol is followed; with co-occurring mental health difficulty CAMHS AMH transition protocol followed; all others transferred through the child/adult ASD transition process. |
| **Date of Protocol** | Not dated | Not dated | Sept 2011; revised 2016 | March 2015 | Dec 2014 |

Key: SU Service User, KW keyworker, MDT Multi-Disciplinary Team, YP Young person

## 3.5 Chapter 3 Summary

- Sixteen core teams deliver the CAMH services at a local level across the five HSC Trust areas.
- Five services are available at a regional level: The Inpatient Adolescent Unit and the Eating Disorder Youth Services located in Beechcroft; The Family Trauma Centre; Knowing Our Identity service; and the Forensic Child and Adolescent Mental Health Service.
- Overall, from 2014/2015 approximately 9000 young people had been referred to one of the services, with 4618 open cases.
- At the time of data collection, a total of 214 FTE staff were employed across the 5 Trusts, providing a ratio of 1 staff member to 22 patients. Reflecting the specialist services offered in the Belfast and Southern Sector, this Trust had the lowest staff patient ratio (1:17). Among the other Trusts, the ratio was broadly similar, ranging from 1:25 (WHSCT) to 1:30 (NHSCT)
- There is no regional policy or protocol with regard to the transition of young people from CAMHS to AMHS in Northern Ireland. Each of the five HSC Trusts has developed their own protocols. The BHSCT and the SEHSCT share the same protocol with local variations. The WHSCT includes a separate section on the transition of young people with ASD to adult services, and the BHSCT & SEHSCT transition protocols include the specific guidelines for those making the transition from local CAMHS to the EIT.
- The transition boundary from CAMHS to AMHS is 18 in all 5 Trusts but referral to adult services can occur 6 months before the transfer date. In some circumstances young people remain with CAMHS beyond their 18$^{th}$ birthday, this is particularly the case for young people with ADHD. The transfer process is discussed with the service user and, where appropriate, the family. Permission to commence the transfer is sought from the service user in all but one Trust
- All CAMHS teams indicated that they either 'always' or 'sometimes' fulfil 6 steps in relation to the transition, including, joint meetings, handover of documentation, and parent/carer and SU involvement in decision.
- All CAMHS teams named C&V organisations to whom they either transfer clients or work alongside in providing care to young people.
- Accurate data on the numbers of potential and accepted referrals were not available from the returns from all Trusts. Data from the BHSCT indicate that 25% of referrals to adult services are not accepted. In the SEHSCT, the ND&A team estimate that of the 62 young people who had been referred to adult services in the previous year only one third were accepted (i.e. two thirds not accepted). No data on the number of referrals were available for the Southern HSCT. Similarly, the NHSCT was unable to provide exact statistics, but

an estimate was made of 30-50 potential referrals per year, all were accepted. The WHSCT estimated between 60-80 potential referrals each year, with 50 referrals accepted each year (i.e. between17% to 38% of referrals not accepted by adult services).

# CHAPTER 4: STAGE 2 RETROSPECTIVE CASE NOTE REVIEWS

## 4.1 Aim and objectives

The aim of this stage was to evaluate the process of transition using a case note survey to (a) trace service user progression through service boundaries, and (b) examine their outcomes in terms of referral process and level of engagement with services. We therefore attempted to establish the presence of on-going need and if such cases were referred to AMHS. Additionally, we sought to detail the reasons for non-referral and failure of referrals to AMHS (e.g. not referred to AHMS because of a lack of an appropriate service; client refusal; or not accepted by AMHS); characteristics of those seen or not accepted by AMHS; and factors associated with engagement and disengagement with AMHS at 3 and 6 months after first appointment attended.

## 4.2 Methods

The notes of all service users eligible for inclusion to the study were identified through a combination of searching the electronic records and a manual search by the researchers and Trust staff. We also sought the assistance of service managers who were able to identify additional missing cases. An inter-rater reliability test was performed in the initial stages of data extraction checking the proforma for coherence. From records, we identified all people in services during the study period, recording the referral date, referral problem, date seen, diagnosis, treatment provided, engagement with service and outcome (discharged or case still open). We identified the following:

(1) Patients at the appropriate age for transition (locally defined by protocol) and considered for transfer and/or expected to have on-going needs;

(2) Patients still being seen by CAMHS because of the lack of an adequate/appropriate adult service;

(3) Patients discharged or disengaged from CAMHS with a continuing mental health problem (but not to AMHS).

From the AHMS database we identified individuals referred to AHMS including those below the recognised age cut-off.

### *4.2.1 Selection/Recruitment*

The TRACK study in England indicates that the rate of transition from CAMHS to adult care is about 20 adolescents per million of the general population per year with another 10 potential cases (as defined previously). We estimated that a sample size comparable to that collected by Singh and colleagues would be achieved by collecting data from four years of case note examination. Thus, we aimed to record data on 168 transition cases.

### 4.2.2 Criteria for inclusion

The criteria for inclusion in the study

- Young person attended CAMHS between January 2010 and December 2014
- Who reached the transition boundary (age 18) in that time period

In addition to this group, all young people attending CAMHS in the Belfast and South East Sector who were age 16 between January 2010 and December 2014, whether they reached transition or not, were eligible for inclusion in a subset of the review.

### 4.2.3 Accessing CAMHS and AMHS charts

The Data Protection Act governs the examination of patient case notes for research purposes. Initially, it was agreed with the Trusts that the transfer of anonymised data onto the proforma data sheets would be done entirely through the Trusts' audit departments. However, the Audit Departments could not guarantee dedicated time to the project and eventually, we were permitted to collect hospital service data from the Trusts directly with the support of Trust staff. Once the information was transferred from case notes to the proforma, case records were not consulted again. All data collection was carried out on Trust premises. Contact details of the lead researcher were provided for further advice about the study.

A meeting with CAMHS team managers in each of the Trusts was arranged to discuss the retrieval of the CAMHS patient charts and the logistics of this. Contact was subsequently made with designated administrative staff and the criteria for retrieval forwarded to them. Different databases and information systems operate across the Trusts. As a result it was not possible for administrative staff to easily identify all those who met the criteria for inclusion in the review across the five Trusts. For example, not all CAMH service databases recorded whether or not a young person was referred to AMHS, or the destination of those who reached eighteen. Not all had the relevant information for the time period. Some depended on minutes from transition meetings and handwritten bookkeeping records to identify the potential referrals. It was therefore not possible for IT or administrative departments to run queries or manipulate reports to comprehensively produce the information required across all HSC Trusts.

- BHSCT and SEHSCT: the administrator coordinated the retrieval of patient notes (for all who were 16 and over and receiving care from CAMHS between 2010 and 2014) from each of the teams, or from storage sites. All relevant notes were delivered to one location for review. Reviewers identified all service users, from these notes, who reached 18 years and met the criteria as a potential referral. A list of these potential referrals, with database number and/or hospital number, was returned to the administrator in CAMHS who then identified the adult team each individual moved to.

Researchers subsequently contacted the adult teams and arranged to review the relevant notes at their clinic.

- SHSCT: The notes for young people who reached eighteen between 2010 and 2014 and were referred to adult services were retrieved. The list generated by CAMHS was sent to the three adult sites and corresponding adult notes were reviewed where available.
- NHSCT: a comprehensive list of those who were aged 18 or over between 2010 and 2014 and who were referred to adult services was generated by the IT department. The administrative staff in CAMHS retrieved the majority of these notes for review, although not all met the inclusion criteria. The Clinical Studies Officer who was based in the Northern Trust made initial requests to the Adult teams for corresponding adult notes, the majority of these were made available and reviewed at the relevant clinics.
- The WHSCT used the minutes from their Transition Panel meetings from 2012 to 2014 to generate a list of potential referrals (i.e. named at a Transition meeting) in that time period. Information on the number of referrals prior to 2012, and prior to the Transition Panel, was not easily accessible. A Trainee Psychiatrist based in the Western Trust requested the corresponding Adult notes for Service Users who actually made the transition to adult services from this list. All available AMHS notes were reviewed at their location.

### *4.2.4 Data collection*

A modified version of the TRACK questionnaire (Singh et al, 2009) was used to capture the details of transition (actual and potential). These were amended appropriately for the NI context, and were checked for face and content validity with CAMHS and AMHS clinicians. The tools also contained a section on external agency involvement. Thus, we examined (a) GP referral and engagement with treatment and care; (b) other governmental agency, e.g. social care for Looked After Children (LAC), and (b) voluntary sector agency involvement. We recorded the presenting problem at the time of referral, outcome of referral to AMHS (accepted by adult services, retained or referred elsewhere), time from referral date to transfer, ease or barriers to transition including quality of information, contact frequency, types of contact and contacting agencies. We noted the existence, timing and level of adherence to a transition care plan and reasons for deviation.

Additionally, we recorded CAMH service use by *all* referrals to CAMHS in the BHSCT and SEHSCT CAMHS irrespective of their later eligibility for transition to adult. These data are of wider importance in identifying patients who may require intervention but disengage from services and may reappear later in adult services. The analysis of this dataset is not included in this report.

### *4.2.5 Data recording*

For all cases the following information was recorded:

- **Patient information:** Socio-demographic data (age, sex, education/ occupation/ training, ethnicity, sexual orientation (where noted). We also recorded the post-code to link to the Northern Ireland Multiple Deprivation Measure (NI MDM 2010), a relative measure of deprivation.
- **Parental and family** information (people living at home and/or if LACs, history of care, history of parental mental health problems and/or drug and alcohol use), employment and occupation was also obtained and indicators of parental engagement (attendance at CAMHS).
- **Service-related information**: referring agency, interval time between referral and assessment referral details; presenting problem and diagnosis, substance misuse, co-morbidity; episodes of self-harm and attempted suicide.

As a pilot exercise, three Trainee Psychiatrists in two sites reviewed a random selection of charts (n=6) and the review forms were adapted. An invitation was sent to other Trainee Psychiatrists via the Royal College of Psychiatrists to become involved in the study. A further twenty-one Trainees attended an information workshop on the project in the Belfast Trust, which was combined with a second pilot of the revised case note review. We reviewed twenty-nine charts at this workshop/pilot in which the Trainees completed a feedback form on the layout, content, instructions, and usability of the case note review form. This information and the feedback received from two Consultant Psychiatrists on the Steering Committee, informed the final version of the Review Form, which as a result was split into three parts, A, B and C.

**Part A** of the review tool was completed for all participants and gathered socio demographic data, family history, information on the reason for presentation at CAMHS, information on the contact with CAMHS, interventions, and outcome or destination on leaving CAMHS.

**Part B** was completed for all those who reached the transition boundary (potential referral) and documented what happened to the young person at this time, and the nature of any referral made to adult services.

**Part C** was completed for those who were referred and accepted to adult services (actual referral) and collected data on the handover of care, nature of contact with AMHS and interventions received, and the outcome for the service user.

## 4.3 Findings

### *4.3.1 Participant Overview of Those Eligible for Transition*

Three hundred and seventy-three service users were eligible for transition between January 2010 and December 2014. The sample included 225 females (60%) and 148 males (40%).

#### *Living arrangements and special needs*

Most service users (n=197, 53%) lived with parents who were married or cohabiting; 35 young people (9%) were recorded as looked after children (LACs) or cared for by people outside the immediate family. Fifteen (4%) were present on the Child Protection Register.

Thirty-four service users (10%) were recorded as having a Special Education Need (SEN) and 27 (8%) were involved with a Youth Offending Team.

#### *Deprivation*

Area deprivation data was retrieved via postcodes using the Northern Ireland Research and Statistics Agency's Multiple Deprivation Measure (MDM). Deprivation scores on the MDM range between 1-580, with 1 being the most deprived area and 580 being the least deprived. These scores were organised into quartiles and young people were placed in deprivation quartiles based on their score. The distribution of cases within the quartiles is similar.

#### *Family Members with Mental Health History*

Two hundred and forty four service users (67%) were recorded as having a family history of mental illness, predominantly a mother (n=158). In 183 cases both parents were recorded as having a mental illness. Sibling mental illness was recorded for 62 (26%) people.

### *4.3.2 Referral to CAMHS*

The median age for referral to CAMHS was 14 years (Mean=14.2, SD=3.2). Males were more much more likely to have been referred at a younger age than females (Mann-Whitney test; $z = -3.341$, $P<0.0008$). Additionally, males spent significantly more time within CAMHS than females (Mann-Whitney: $z=3.666$, $p=0.0002$).

Out of 373 CAMHS service users, 261 (70%) were referred by their GP. Forty-seven (13%) were referred to CAMHS through a mental health worker such as a counsellor. Thirty-nine (10%) were referred to CAMHS through a health worker, such as an Accident and Emergency doctor following a suicide attempt or self-harm.

Fourteen (4%) young people were referred via their social worker and seven (2%) were referred via an educational professional such as a school counsellor. The profession making the referral to CAMHS was not recorded for five (1%) young people. The contents of referral letters were examined to explore reasons for referral to CAMHS. The reasons provided in the

case-notes as to why young people were referred to CAMHS are recorded in Table 4.1. They do not, of course, represent diagnoses.

**Table 4.1** Reasons for Referral to CAMHS

| Reasons for Referral | Number of Cases (%) |
|---|---|
| Emotional problems | 215 (58%) |
| Suicidal thoughts or attempts | 97 (26%) |
| Behavioural reasons | 77 (21%) |
| Crisis/complex psychosocial issues | 75 (20%) |
| Eating difficulties | 69 (19%) |
| Suspected ASD/ADHD | 47 (13%) |
| Alcohol or substance misuse | 25 (7%) |
| Poor academic progress | 17 (5%) |
| Family issues | 16 (4%) |
| Aggression | 15 (4%) |
| Psychosis | 9 (2%) |
| Peer problems | 4 (1%) |
| Post-traumatic stress disorder | 4 (1%) |
| Learning difficulties | 3 (1%) |
| Criminal justice system | 1 (1%) |

Upon receipt of CAMHS referrals, Mental Health nurses did most of the initial assessments (36%); while a third were seen by a psychiatrist. Psychotherapists assessed 11 people (3%). The complete list of clinicians involved in the first assessment is given in Table 4.2.

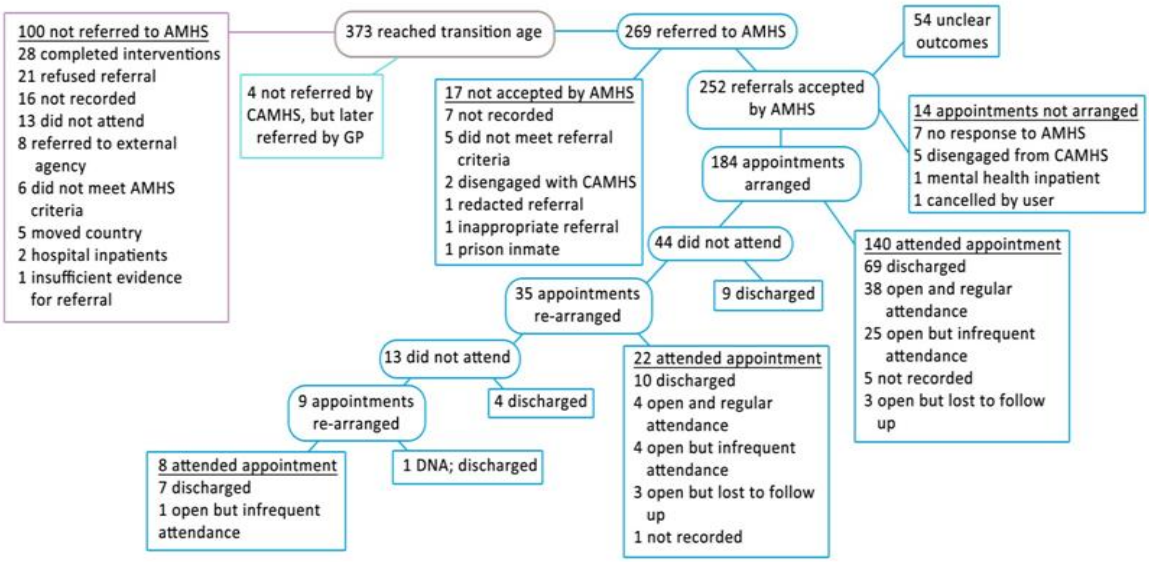
**Table 4.2**: Clinicians involved in initial assessment

| Clinicians Involved in Initial Assessment | Number of Cases % |
|---|---|
| Mental health nurse | 133 (36%) |
| Consultant Psychiatrist | 118 (32%) |
| Social worker | 104 (28%) |
| Clinical psychologist | 45 (12%) |
| Trainee psychiatrist | 34 (9%) |
| Eating disorder practitioner | 30 (8%) |
| Clinical health coordinator | 25 (7%) |
| Mental health practitioner | 12 (3%) |
| Dietician | 9 (2%) |
| Family therapist | 6 (2%) |
| Psychotherapist | 5 (1%) |
| Primary mental health worker | 4 (1%) |

### *4.3.3 Transition pathways - Transfer*

Of the 373 cases recorded as being in CAMHS within the transition period, 269 (72%) were referred to AMHS, of whom, 17 (6.3%) were not accepted. The various reasons for non-acceptance by AMHS are given in Figure 4.0. There was no evidence of a transition meeting having taken place with regard to these 17 unsuccessful referrals, which raises questions with regard to the continuity of care. Thus, 252 people (67%) crossed the transition boundary.

**Figure 4.1**: Transition Pathways




*NB: Data provided by the Western Trust involved young people who transitioned between 2012-2014. Other trusts provided data on young people between 2010-2014*.

#### *Cases Rejected by AMHS*

Out of 252 young people who were successfully referred to AMHS, 13 (5%) were initially rejected upon referral. Reasons for rejection were documented for ten (77%) of these young people. The most common reason for refusal was a failure to meet AMHS criteria (7; 70%). Two people (20%) were referred to an inappropriate service. One person (10%) was currently receiving an intervention for a crisis situation and AMHS did not wish to disrupt this intervention. Continued efforts were made on the part of CAMHS to have these young people successfully referred to AMHS. All of these young people were accepted by AMHS following their second referral to AMHS.

#### *Cases Accepted by AMHS*

This section will discuss referral details for all 252 young people successfully referred to AMHS. Documented reasons why young people were referred to AMHS and the AMHS teams that they were referred to can be viewed in Table 4.3 and Table 4.4 below.

**Table 4.3**: Reasons for Referral to AMHS

| Reasons for Referral | Number of Cases |
|---|---|
| Medication and monitoring | 90 (36%) |
| Medication, treatment and monitoring | 51 (20%) |
| Psychological treatment | 48 (19%) |
| Not recorded | 28 (11%) |
| Medication and treatment | 20 (7%) |
| Monitoring | 17 (7%) |

**Table 4.4**: AMHS Teams to which service users were referred

| AMHS Team | Number of Cases |
|---|---|
| Community Mental Health Team | 134 (53%) |
| Psychiatry Team | 61 (24%) |
| Eating Disorder Team | 32 (13%) |
| Not recorded | 16 (5%) |
| Psychology Team | 11 (3%) |
| Self-Harm PD Team | 2 (1%) |
| Adult Psychotherapy | 1 (<1%) |
| Adult Inpatient | 1 (<1%) |

Referrals were accepted and allocated upon receipt for 175 service users (69%). Twenty-five young people (10%) had their referral accepted by AMHS, but were placed on a waiting list due to service demands. For 24 others (10%), AMHS sought further discussion with the referring clinician prior to acceptance into AMHS; these people were all accepted following discussion. This type of information was not recorded for 28 young people (11%).

#### *Breached referrals*

The date of referral to AMHS and the date of first appointment at AMHS were recorded for each young person. Referrals may be considered 'breached' if it took longer than 100 days between the date of referral and date of first appointment with AMHS. Following this criterion, 60 (24%) referrals can be classified as breached referrals.

### *4.3.4 The Transition Process*

We examined CAMHS notes in order to assess whether the transfer to AMHS had been discussed with service users. A discussion about transfer of care from CAMHS to AMHS with service users was documented clearly in 183 CAMHS notes (73%). Additionally, a transfer of care discussion with the young person's parents or carers was documented clearly in 140 CAMHS notes (56%).

For those who had a discussion recorded in CAMHS notes, the contents of these notes were examined further. Forty-seven clinicians (19%) sought consent from service users to transfer their care to AMHS. Consent to transfer care was considered to be inferred if the young person was happy with the conversation and did not have any concerns. Following this criteria, consent to transfer care was inferred for 128 young people (51%). Forty-one clinicians (16%) clearly documented in their notes that they informed the young person of why they were being transferred to AMHS. Thirty-nine clinicians (15%) recorded clearly discussing the end of the therapeutic relationship between themselves and the young person in their notes.

### *Transition Planning Meeting*

We assessed notes for a documented transition-planning meeting. Such a meeting was recorded in ninety 96 cases (38%) and in 73 (29%) we noted that no meeting took place. Whether a transition planning meeting took place is unclear for 89 young people (33%). Minutes were taken, and included in the notes, at 11 (11%) of these meetings.

### *Transfer of Care*

Transfer of care between CAMHS and AMHS is managed in two ways. Firstly, a joint appointment takes place between CAMHS, AMHS and the young person; this appointment discusses the end of CAMHS' care, and transfer of care to AMHS. Alternatively, the young person is formally discharged from CAMHS during an appointment, and then receives their first appointment with AMHS in succession.

The most prevalent method of care transfer was a sequential appointment with CAMHS and then AMHS (n=128, 51%). Joint appointments between CAMHS and AMHS were less common (n=46, 18%). Of the 100 cases not referred to AMHS, 28 were deemed to have completed treatment and were discharged. A further, 5 people were referred to voluntary sector agencies, moved country (n=5), or referred to Adult Intellectual Disability services (n=3). Twenty-one cases were recorded as refusing referral. Seven did not meet AMHS criteria or lacked evidence of need for referral. In 29 cases the reasons were not recorded or had not been attending. Four young people not referred by CAMHS were later referred by their GPs and accepted by AMHS.

### *Meeting Optimal TRACK Criteria for Transition*

In the TRACK study, the research team suggested four features of an optimal transition:

- **Continuity of care:** This involved receiving an appointment three months following the transition, *or* being appropriately discharged following initial assessment if there was no need for an intervention.
- **Period of parallel care:** This involved a joint appointment with both CAMHS and AMHS.

- **Transition planning meeting:** A transition meeting was held for the young person.
- **Optimal information transfer:** Three main components of information transfer were met – a referral letter, summary of CAMHS contact and CAMHS notes.

While most of the service users who transferred from CAMHS to AMHS, had some level of continuity of care, only a minority had a transition planning meeting or a period of parallel care; none met all four criteria. Likewise, the number of cases meeting the recommended information transfer between services is small.

**Table 4.5** Number of cases with components of Track criteria

| Components of TRACK Criteria | Number of Cases (Out of 252) |
|---|---|
| Continuity of care | 184 (73%) |
| Transition planning meeting | 96 (38%) |
| Period of parallel care | 46 (18%) |
| Optimal information transfer | 8 (3%) |
| Continuity + meeting + parallel care | 1 (<1%) |
| **All four criteria** | **0 (0%)** |

Of the 252 people transferred to AMHS, 100 (40%) were later discharged by AMHS while 72 (28%) remained in attendance. Fourteen people had not received an initial assessment and 6 cases were open but lost to follow up. Information for another 6 people was not available.

### *4.3.5 Analysis of factors related to Transition to AMHS*

We found some significant differences between groups in factors potentially associated with transition to AMHS (Table 4.6). However, using logistic regression analysis, we found that years of contact with CAMHS (Table 4.7) and HSC Trust (Table 4.8) were significantly associated with transition. A prescription for anti-psychotic medication was the strongest predictor of transition (Table 4.9). Neighbourhood deprivation (NI-MDM) had no significant effect on transition (Table 4.10).

**Table 4.6**: Transition from CAMHS to AMHS

| | | Total % (n) | Not transitioned % (n) | Transition to AMHS % (n) |
|---|---|---|---|---|
| Gender | Male | 39.7 (148) | 21.6 (32) | 78.4 (116) |
| | Female | 60.3 (225) | 32.0 (72) | ns 68.0 (153) |
| Health Trust | Belfast/South East | 35.2 (131) | 58.0 (76) | 42.0 (55) *** |
| | Southern | 9.9 (37) | 2.7 (1) | 97.3 (36) |
| | Western | 14.5 (54) | 31.5 (17) | 68.5 (37) |
| | Northern | 40.8 (151) | 6.6 (10) | 93.4 (141) |
| Deprivation levels (Based on NI-MDM employment domain) | Most deprived quartile | 28.1 (96) | 29.2 (28) | 70.8 (68) * |
| | 2: | 24.3 (83) | 19.3 (16) | 80.7 (67) |
| | 3: | 21.6 (74) | 20.2 (15) | 79.7 (59) |
| | Least deprived | 26.0 (89) | 39.3 (35) | 60.7 (54) |
| Deprivation levels (Based on NI-MDM summary domain) | Most deprived quartile | 28.1 (96) | 28.1 (27) | 71.9 (69) ns |
| | 2: | 22.8 (78) | 25.6 (20) | 74.4 (58) |
| | 3: | 21.1 (72) | 20.8 (13) | 79.2 (57) |
| | Least deprived | 28.1 (96) | 33.3 (32) | 66.7 (64) |
| Structure of family | Both parents present | 53.7 (197) | 27.4 (54) | 73.7 (143)ns |
| | Single parent household | 36.2 (132) | 28.0 (37) | 72.0 (95) |
| | Other | 10.0 (36) | 27.8 (10) | 72.2 (26) |
| Number of years in CAMHS services | Up to one year | 28.4 (106) | 29.3 (31) | 71.8 (75) |
| | Two years | 22.8 (85) | 36.4 (31) | 63.5 (54) |
| | Three to four years | 27.4 (102) | 31.4 (32) | 68.6 (70) |
| | Five or more years | 21.5 (80) | 9.6 (10) | 87.5 (70) ** |
| Family History of mental health problems | Mother or father | 49.6 (183) | 22.7 (44) | 76.3 (142) * |
| | Other family | 16.5 (61) | 40.3 (25) | 59.7 (37) |
| | None recorded | 33.9 (125) | 28.0 (35) | 72.0 (90) |
| Age of client at first contact with CAMHS | 1-9 years | 10.8 (39) | 10.3 (4) | 89.7 (35) * |
| | 10-14 years | 29.1 (105) | 26.7 (28) | 73.3 (77) |
| | 15-16 years | 31.8 (115) | 34.8 (40) | 65.2 (75) |
| | 17+ years | 28.5 (103) | 30.1 (31) | 69.9 (72) |

ns= non-significant * p<0.05 **p<0.005 ***p<0.0005

**Table 4.7**: Transition to AMHS services, by (a) age of client at first referral, and (b) years the client known to the CAMHS service. (Odds Ratio of Likelihood of Transition to AMHS)

| | Categories | OR (95% CI) |
|---|---|---|
| Age of client at first referral to CAMHS | 1-9 years | 1.00 |
| | 10-14 years | 0.34 (0.11, 1.04) |
| | 15-16 years | 0.24 (0.07, 0.73)* |
| | 17+ years | 0.30 (0.10, 0.91)* |
| Number of years client was known to CAMHS | Up to one year | 1.00 |
| | Two years | 0.72 (0.39, 1.32) |
| | Three to four years | 0.90 (0.50, 1.63) |
| | Five or more years | 2.89 (1.32, 6.34)** |

Odds Ratios (OR) refer to the likelihood of transition to AMHS
Models additionally adjusted for gender

**=P<0.001; P<0.05

**Table 4.8**: Transition to AMHS services, by Health Trust (Odds Ratio of Likelihood of Transition to AMHS)

| | Categories | OR | (95% CI) |
|---|---|---|---|
| Health Trust | Belfast/South East | 1.00 | |
| | Southern | 49.23 | (6.48, 374.34)*** |
| | Western | 19.39 | (9.29, 40.47)*** |
| | Northern | 3.00 | (1.52, 5.89)** |

Odds Ratios (OR) refer to the likelihood of transition to AMHS
Models additionally adjusted for gender
***: p=0.000; **=P<0.001

**Table 4.9**: Prescribed medications prior to transition from CAMHS to AMHS (Odds Ratio of Likelihood of Transition to AMHS)[9]

| | % (N) | Univariate analysis OR (95% CI) |
|---|---|---|
| Hypnotics | 26.5 (99) | 1.06 (0.21, 0.75) |
| Anxiolytics | 2.1 (8) | 2.22 (0.26, 18.64) |
| SSRIs | 53.1 (198) | 0.83 (0.42, 1.63) |
| Non-SSRIs | 7.8 (29) | 1.10 (0.42, 2.88) |
| Benzodiazepines | 5.4 (20) | 1.09 (0.35, 3.45) |
| Beta-blockers | 2.7 (10) | 0.67 (0.16, 2.72) |
| Stimulants (ADHD medication) | 16.9 (63) | 1.89 (0.79, 4,55) |
| Anti-psychotic medication | 29.0 (108) | 2.75 (1.39, 5.40)* |
| Dietary supplements | 3.0 (11) | 3.67 (0.46, 29.52) |

**Table 4.10**: Referral to AMHS, by selected NI-MDM multiple deprivation domain indicators[$]. Odds Ratios (OR) refer to the likelihood of transition to AMHS

| | Education OR (95% CI) | Health OR (95% CI) | Income OR (95% CI) | Summary OR (95% CI) |
|---|---|---|---|---|
| Most deprived | 1.00 | 1.00 | 1.00 | 1.00 |
| 2: | 1.69 (0.86, 3.30) | 1.73 (0.87, 3.41) | 1.87 (0.94, 3.75) | 1.14 (0.58, 2.26) |
| 3: | 1.75 (0.86, 3.58) | 1.32 (0.66, 2.64) | 1.75 (0.87, 3.54) | 1.56 (0.75, 3,24) |
| Least deprived | 0.71 (0.36, 1.36) | 1.13 (0.61, 2.12) | 0.77 (0.41, 1.46) | 0.82 (0.44, 1.53) |

[$]: NI-MDM are a standard measure of area-level deprivation derived by NISRA (the Northern Ireland Statistics and Research Agency). They are routinely updated – these dates refer to 2010.

## 4.4 Chapter 4 Summary

- The case note review found 373 (225 females and 148 males) service users were eligible for transition between Jan 2010 and December 2014.
- Over half (53%) lived with parents who were married or cohabiting, approximately 1 in ten (9%) were recorded as LAC or cared by people outside the immediate family. 15 were on the child protection register. One in ten had SEN and 8% were involved with the youth offending team.
- No significant difference was recorded on the number of young people attending CAMHS according to NI multiple deprivation scores.
- The median age for referral to CAMHS was 14 years. Males were more likely to be referred younger than females. Most (70%) were referred by their GP. Mental health workers or

counsellors and A&E staff referred 23%. Social work or educational professionals referred 6%.

- Of the 272 cases recorded as being within CAMHS within the transition period, three quarters (269) were referred to AMHS, of which 6% (17) were not accepted. Thus, just over two thirds (67%) of the young people crossed the transition boundary.
- From the 252 young people who were referred to AMHS, 175 cases were accepted and allocated, 25 had their referral accepted and were placed on a waiting list, and a further 24 had their cases discussed with the referring clinician before acceptance. Five percent (13) were rejected on referral.
- A quarter (60) of referrals were described as breached (i.e. number of days to first appointment longer than 100 days).
- A discussion about the transfer of care was recorded in approximately three quarters (73% 183 cases) of the CAMHS notes; and a transfer of care discussion with parents/carers was documented in just over half (56% 140 cases).
- There was no evidence of any young person experiencing an optimal transition (i.e. meeting all 4 features identified in the TRACK study): 46 (18%) experienced a period of parallel care; 96 (38%) cases were discussed at a Transition Planning meeting.
- Formal consent was sought from the service users in only one fifth (22%) of cases. Consent was inferred if the young person was happy with the conversation and did not have any concerns (51% of cases).
- Of the 252 young people transferred to AMHS, 100 (40%) were later discharged while 72 (28%) remained with AMHS.
- The strongest recorded predictor of transition to AMHS was prescription of anti-psychotic medication.
- The number of years contact with CAMHS and which Trust a young person resided in were strongly associated with transition to AMHS.

# CHAPTER 5: STAGE 3 CONSULTATION WITH YOUNG PEOPLE, CARERS AND SERVICE PROVIDERS

## 5.1 Aim

The aim of this stage of the research was to construct a more finely grained understanding of the experiences and needs of a range of young people (and their carers) in the transition into adult care. Using qualitative interviews, the research aimed to describe the transition experiences of the service users, parents/carers and keyworkers/practitioners within CAMHS and AMHS, and to explore the barriers and facilitators to the transition process. The research also explored service users' perspectives on service engagement and inclusion in decision-making processes.

## 5.2 Methods

This stage of the research involved a qualitative study to follow the experiences of service users (SUs), pre and post transition from CAMHS (eighteen young people were interviewed about their experience of mental health services and their preparation for transition, ten of these were interviewed following their move to adult services). In-depth interviews were carried out with a sample of carers whose son or daughter had experience of transition (n=12). Eighteen keyworkers or clinicians in CAMHS and AMHS were interviewed in relation to the transition experience of those involved in the study. Additional perspectives on transition were obtained through interviews with service commissioners and policy-makers and with practitioners in the voluntary sector.

In addition, towards the end of project, a one-day workshop was convened to present the preliminary findings to a large group of service users, family members and clinicians and academics. In all, forty-one people attended: 10 from CAMHS, 10 from AMHS, 10 from CVS and 11 others which included service users, parent/carers, advocates, commissioners, researchers and academics). The aim of the workshop was to synthesis and report on the study findings, and to gain participants' feedback to inform the recommendations for service change.

### *5.2.1 Sampling and recruitment*

Potential participants for the in-depth interviews (young people approaching the transition boundary, their family carers and professional carers) were identified by staff in the CAMHS teams. The informal carers were a parent or guardian usually the primary carer, who were only approached for interview with the permission of the service user. The professional carers were consultant psychiatrists, psychologists or social workers, one of whom was a keyworker with regular contact with the SU and family. The service users were contacted initially via their CAMHS keyworkers. Letters with information about the project (see Appendix 7) were sent

out to the Team Managers and Clinical Leads in the various teams within the five Health and Social Care Trusts in August/September 2015. The letters enclosed information for keyworkers on recruitment and leaflets for young people. These letters invited the Team Managers and Clinical Leads to identify service users who met the following inclusion criteria:

- Being considered for transfer to Adult Mental Health Services (AMHS);
- Expected to make the transition from CAMHS to Adult Services between September 2015 and December 2015; and
- Willing to be interviewed by a member of the IMPACT research team at a time and place of their choosing

### *5.2.2 Data collection tools (Stage 3)*

Interviews and focus groups were the main source of data collection for this stage of the research. Feedback from the interactive workshop was gathered by both focus groups and an anonymous self-completion questionnaire.

Informed by the literature and from preliminary hypotheses emerging from data analysis (interviews and case note survey in stages 1 and 2) we constructed different but somewhat overlapping topic guides for SUs and carers. The SU topic guide was developed with the help of young people in VOYPIC. A priori, we were interested in how young people constructed or perceived their problems and how consonant (or dissonant) such perceptions and attributes might be with medical or social care descriptions of the problem. Additionally, we sought to explore concepts of recovery for young people in this early stage of service provision.

Thus, for the SUs we explored:

(1) The participant's explanatory model of the problem (illness, severity, impact and expectations of treatment);
(2) Pathways into care (history of service contact, including GP involvement and help-seeking behaviour);
(3) Young persons' concepts of recovery as related to (a) social, education and employment needs; (b) hopes and plans for the future.

At follow up**,** we contacted SU participants in order to discuss what happened during and following the expected transition and what services were involved in their care (including community and GP). We also explored each participant's engagement with services across a range of domains (including for example, their involvement in planning of care, information giving, and inter-agency liaison). We sought to clarify SU recovery-related issues and how these had advanced or deteriorated.

The topic guides for parents/carers covered the following areas:

- Their understanding of the problem;
- Quality of care by services including continuity of care;
- Information giving and sharing;
- Their involvement in planning and decision making processes; and
- Their contact with other services including GP and voluntary sector.

During the interviews, we also explored the carers' hopes and expectations for their family member. In some cases where a particular failure of services appears to have occurred, it was necessary to supplement interviews with a wider retrospective review to examine how: (1) the future service needs of the young person were discussed, (2) what action plans were put in place to meet these needs, (3) how the young person was prepared for transition to the new service; and (4) what decision making processes and dynamics were in place.

Key workers and clinicians in both CAMHS and AMHS were interviewed to gain insight into the transition process from their perspective. We were interested in the practicalities of the process, the application of policies and protocols, the service provider experiences of what works well and any problems encountered.

The topic guide for clinicians covered the following areas:

- History of care within CAMHS
- Transition planning
- Transition issues
- Comparison of Adult services to CAMHS, including perception of 'other' service
- Potential impact of transition on Service User
- Other sources of support

Multidisciplinary focus groups were held to further explore these issues.

A semi structured interview schedule was used to guide these discussions and covered the following topics:

- Current transition policies and procedures
- Management of the transition process (including service user and carer involvement, and resource issues)
- Determining or influencing factors on successful transition outcomes
- Suggestions for improvement or change

Further consultations with service providers were conducted during the interactive workshop and involved both focus groups (using a pre-agreed topic guide) and an online survey. The online survey was sent to all attendee and provided an opportunity to provide 'private' feedback on the discussions on the day. The survey included a set of statements describing the themes from the day. Respondents were asked to score each of the statements on their importance in relation to the improvement of the transition process. They were also offered an opportunity to provide additional comments and thoughts on the day.

### *5.2.3 Data analysis (Stage 3)*

Framework analysis (Ritchie & Spencer, 1994) was used as a method to analyse the interviews and focus groups. This process involves a set of procedures of familiarisation to build thematic frameworks, coding and charting (Miles and Huberman 1994). Two of the researchers each read the interviews to gain a sense of the data and to develop an initial coding frame for each set. They then met to discuss the process and to cross code each other's transcripts. Initially three separate coding frames were developed, (for service users, parent/carers and keyworkers) these were subsequently merged into one coding frame. This coding frame was sent to the steering group, together with a random selection of anonymised interviews from all three of the core participant groups. Amendments to the initial coding frame were made based on the feedback from the steering group. NVivo, a software programme for qualitative data analysis, was used to code the data. Patterns or commonalities of behaviour and events in the transition pathway were examined, as were irregular cases that arose for particular individuals, settings or from unusual circumstances. The significance of these in terms of service failure and unsatisfactory service provision was considered. While service user and carer transcripts were examined and reported separately we also looked at the overlap and divergence in reported experiences.

The data transcripts for all stages of the fieldwork together with the field notes and any relevant documents (e.g. policies that influence service delivery) were analysed within NVivo. The analysis process of interrogation and refinement clarified the difficulties and barriers to the provision of good health and social care by revealing underlying factors and processes, as well as highlighting the components of successful transition good care. The analysis sought to explain linkages between actors and agencies, and between structural and cultural factors. The analysis and findings allowed us to build an initial but comprehensive set of recommendations. Supported by material from all stages and elements of the project we developed vignettes and anonymised case studies to assist an exploration of complex and potentially contested layers of service user experience in order to stimulate facilitated interactive discussions with health professionals and managers.

## 5.3 Sample description (Stage 3)

Eighteen young people agreed to participate in the study. An initial meeting was set up with the researcher and the service user, with the knowledge of the key worker. Where possible, this initial interview with the young person (Round 1) took place while they were still in the care of CAMHS, and prior to them making the transition to Adult Services. Young people who participated in interviews received a £15 gift voucher per interview as recompense for their time.

During the Round 1 interviews/meetings with the service users, the researcher established when the service user anticipated their transition to adult services would take place, and if they were happy to be interviewed again after that transition. A member of the research team subsequently re-contacted the service users to invite them to participate in a follow-up interview (Round 2) following their transition to AMHS (between 1 and 3 months post-transition). Ten of the eighteen service user participants were interviewed at both Round 1 and Round 2. We were unable to re-interview four of the other eight individuals, after their transition to Adult services, and four were recruited having already made the transition to adult services. Initially, we aimed to interview service users at three time points; (1) prior to transition; (2) after transfer to adult services; and (3) three months after transition We revised this plan when it became clear that a third interview was not feasible and might not produce any significant new data to that collected at Round 2. In order to capture the experience of service users who had been with adult services over a longer period of time we interviewed four young people post transition only. When each Round 1 service user interview was completed we then sought the service user's consent to interview their parent/carer. Some young people did not want their parents to be interviewed or assumed that they would not want to take part. Where permission was given, a member of the research team contacted the parent, usually by telephone, to provide information on the study and invite them to participate. Field notes were written after each interview and followed a set format. The overall profile of the research sample for this stage of the research is presented in Table 5.1.

**Table 5.1:** Profile of research sample – Stage 3

| Population | Detail |
|---|---|
| Young people | **N=25**<br>**Core group (n=18):**<br>***Meeting 1*:** 10 female, 6 male, 2 transgender<br>Living at home (n=17); Living independently (n=1)<br>***Meeting 2***: Repeat interviews (n=10) (4 female, 4 male, 2 trans)<br>Living at home n=9 Living independently n=1)<br>**Supplemented sample (n=7):**<br>Purposive sample (6 female, 1 male, all 18+) |
| Parents/Carers | **Individual interviews (N=12)**<br>Individual interviews with parents/carers (*related to core group of SU)* n=7<br>Individual interviews with parents/carers of children who had recently made the transition (*but were not part of the core group*) n=5<br>***1 focus group with parents/carers*** *(n=5)* ***(****not related to core group of service users)* |
| Service Providers | **N=26**<br>**Individual interviews (n=26)**<br>Practitioners from AMHS / CAMHS who were keyworkers or psychiatrists for the core group (n=18)<br>Team managers or key staff from Primary Care Liaison, Recovery College, Addiction Team, and CAMHS/AMHS psychiatry (n=8) |
| Workshop participants | **N=32**<br>4 focus groups<br>Multidisciplinary (statutory and CVS groups) and service users. |

### *5.3.1 Profile of young service users*

The young people who took part in this study were recruited from the five Trust areas in Northern Ireland and all had experience of mental health services; a few experienced inpatient care. All but one of the core group of eighteen service users lived at home when we first met them; two others had moved out by the second interview. Ten of the eighteen were interviewed twice, initially when they were in the transition process, and subsequently when they moved into adult services. Four were interviewed post transition only, and four while they were in the transition process only. Of the latter, one young person did not respond to the invitation to meet for a second interview, one did not turn up for an arranged interview, one was willing to be interviewed but was admitted to inpatient care. Another person cancelled two arranged interviews. We were informed by another interviewee, that this person found the move to adult services very difficult and had experienced deterioration in his mental health.

In addition to these eighteen participants, we purposively recruited seven other young 'experts by experience' and we have included their views and experiences in this report. The latter participants had either made the transition into adult services a few years prior to interview, were at the point of transition, or had opted out of statutory mental health services and were receiving support from the community and voluntary sector.

### *Nature of the problem/diagnosis/presentation*

Twelve of the eighteen service users had been diagnosed with depression or low mood at some stage. Ten people described how they had experienced suicidal ideation or a suicide attempt. Self-harm, anger/aggression and anxiety were other frequently quoted symptoms of the mental health problems experienced by the service users. A summary of the problems, presentations and diagnoses is presented in Table 5.2.

**Table 5.2:** Nature of the problem/presentation/diagnosis of the young people interviewed

| Nature of problem/presentation/ diagnosis | Frequency |
|---|---|
| Depression or low mood | 12 |
| Suicidal ideation or attempt | 10 |
| Self harm | 9 |
| Aggression or anger | 8 |
| Anxiety | 8 |
| Mood swings | 4 |
| Withdrawal or isolation | 4 |
| ADHD | 4 |
| Alcohol/substance misuse | 4 |
| Disordered Eating | 4 |
| Learning Difficulties | 3 |
| Auditory/visual hallucinations | 2 |
| ASD/Asperger's/Tourette's | 2 |
| Gender Dysphoria | 2 |
| Unstable/Borderline Personality Disorder | 2 |
| PTSD | 1 |
| OCD | 1 |
| Psychotic depression | 1 |
| Nightmares | 1 |
| Poor self-care | 1 |

### *Triggers and Precursors*

Service Users and Carers attributed the onset of the young person's mental health problems to various issues or events, the most frequent of these were bullying, (a contributing factor for nine young people), general school related stress or trouble, (which was mentioned in the case of six young people), and family breakdown, mentioned by six and linked for three of these with parental alcohol abuse and subsequent separation. Three young people experienced problems related to bereavements, and three talked about the impact of a sexual assault on their mental health. Other triggers mentioned included the breakdown of a romantic

relationship, the effect of dealing with their own or their parent's physical illness. The triggers or precursors to deterioration in a young person's mental health were not clearly defined and young service users' accounts point to the interrelationship and pressures of the different worlds they occupy and navigate.

### *5.3.2 Parents/carers*

Twelve individual parent/carer interviews were carried out. Seven of the parents/carer participants were related to the Core Group of service users. We also conducted individual interviews with five parents/carers of children who had recently made the transition to adult services or were at the point of transition but whose children were not interviewed. A further group of 5 parents, recruited through a support group, were interviewed in a focus group setting. All parents/carers provided information on their experience of contact with services.

### *5.3.3 Service providers*

A total of 26 service providers were interviewed during this stage of the study. Eighteen practitioners from CAMHS or AMHS were interviewed in their capacity as keyworkers or psychiatrists for the core group. We were able to interview a keyworker for 16 of the 18 service users involved in the study (10 CAMHS keyworkers; 3 AMHS clinicians, 1 keyworker from the Early Intervention Team; and 1 keyworker from the community and voluntary sector). Some of the clinicians interviewed were keyworkers for more than one of the service user participants.

A further eight team managers or key staff members from Primary Care liaison, Recovery College, Addiction Team, and CAMHS and AMHS psychiatry were interviewed.

Towards the end of the fieldwork, an interactive workshop was convened to share the initial findings, and to gain stakeholder feedback to inform the final recommendations of the study. A total of 42 participants, representing CAMHS and AMHS service providers, C&V and service users, attended the event. At the end of the presentations, participants (n=32) were allocated to multi-perspective focus groups to discuss the emerging findings and issues. The focus groups explored how the transitional pathway might be improved for young people and their families, how service users might be involved in the process, and how to provide information to young people about the transition. The focus group also explored how young people's perceptions of services can impact on the transition, and sought the groups' views on how young people can be properly informed about the process.

The individual focus groups were recorded and transcribed. A summary of the focus group discussions was relayed to the plenary group. The responses to each question were analysed separately in the first instance, and the main themes or responses recorded.

The data from the interviews and focus groups with service providers conducted during Stage 3 of the research were combined with the data generated during interviews and panel meetings conducted in Stage 1. The findings of the analyses are presented in three parts. Part 1 presents key themes emerging throughout the transition journey (See Figure 5.1). Part 2 presents emergent themes important throughout the journey (See Figure 5.2), and Part 3 describes the impact of different structural processes on the transition (see Figure 5.3)

## 5.4 Stage 3 Findings Part 1: The experience of transition

Part 1 analysis has 6 sub-themes (see Figure 5.1) with a focus on the transition journey, describing young people's, parents/carers', and services views and experiences of CAMHS through to adult services. The analysis also incorporates the barriers and facilitators for transitions, and describes different viewpoints and experiences on the theme of recovery.

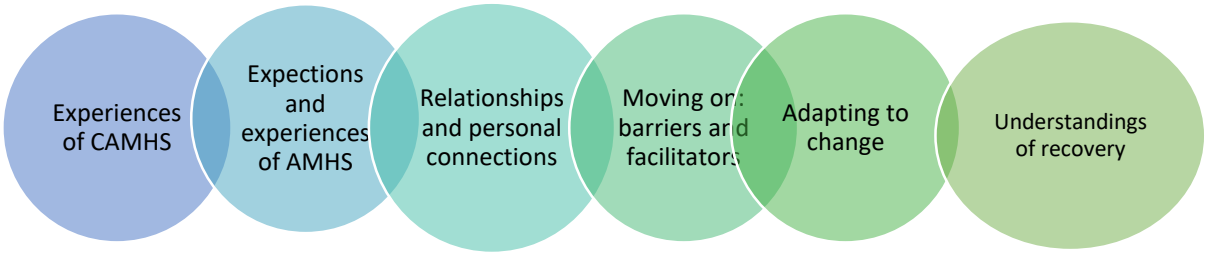



**Figure 5.1**: Part 1 analysis: The experience of transition

### *5.4.1 Experiences of CAMHS*

Within this category, three subthemes on the experiences of care emerge:

- pathways to care;
- aspects of care in CAMHS; and
- parental involvement

#### *Pathways to care*

Most young people accessed mental health services via their GP accompanied by a parent, a few initiated the request for help themselves, by asking their parents to bring them to the GP or to CAMHS. One young person initially contacted a private counsellor. The waiting time between a GP appointment and initial assessment with CAMHS ranged from a few hours to a couple of months. Most reported receiving an appointment with CAMHS within days or a few weeks. While the care pathway at this initial stage was, for most people, straightforward, some experienced problems. For example, one mum described how she was told by the GP that

her son's behaviour was due to drug use and a referral to CAMHS was made only when she continued to request, and insist, on help. Another young woman described several unsuccessful attempts to access help, first through her school, and then via the GP. Her referral to CAMHS was rejected initially and she was re-referred and only accepted one year later when she became suicidal. In a couple of cases, friends played a role in the referral process. For example a young man recognised that he had the same symptoms of OCD and depression with which his friend had been diagnosed and requested his parents to bring him to the GP. Another participant finally gave in to her friends' request that she seek help for her low mood and change in disposition.

### *Aspects of care in CAMHS*

A contextualisation of the issues associated with transition may be better informed by the elements of care within CAMHS that young people and parents valued or found helpful. This data helps us to appreciate the significance of the transition experience and the move to adult services, for service users and parents. The aspects of CAMHS care that young people and parents valued are summarised within four sub-themes:

- ethos and culture of care;
- accessibility and support;
- relationships; and
- authenticity of caring

### *Ethos and Culture of Care*

The ethos and culture of care relates to how the service was delivered and the nature of the relationships with staff delivering the service. Young people and parents valued CAMHS as a service that was trustworthy, accessible, available and responsive. Confidentiality was highlighted as an important element in building this trust:

> *I think it's good because they keep you just, it's confidential, they keep you in a room by yourself. Some rooms are closed space and some are open, but either way they sort of make it in a way that you just know you can tell them anything, and even though there was some stuff that took me a while to say to them because it was so difficult to talk about, I still told them because they were very trustworthy people and I knew it would help if I told them. And it did help.* [Lisa, Service User]

> *Just being able to talk to somebody and know that it's not going to go anywhere else. It's there in a file and it's locked away. Being able to trust somebody, it's just easier.* [Christine, Service User]

While young people acknowledged that some things needed to be shared with parents and carers, they also expected that some things would remain confidential. When they perceived their confidentiality to have been broken, without justification, patient-practitioner engagement was undermined and the therapeutic relationship damaged. One person described how he refused to continue seeing a locum psychiatrist after a few months when she *'broke his confidentiality twice'* by telling his parents information that he assumed was shared with her in confidence.

> *I think confidentiality is a big point, that's what tore a breech between me and the first locum, and then a few other things.* [Paul, Service User]

In the quote below, another participant accepted the limitations of confidentiality and that parents and social workers were kept informed of her contact with CAMHS, but felt this line was crossed when her counsellor shared information with her social worker. It undermined the trust with her keyworker and did not help an already faltering relationship:

> *I think that's what didn't really help it. Cos you were going in there trying to trust and build a rapport with that person, but maybe there's things that you're talking about that you don't want shared round with everybody. There's things that need to be disclosed and there's things that are not necessary but then if they're all coming in together then things get shared that maybe shouldn't [ ] cos they tell you at the start [said in stilted voice] 'We- will- not- disclose -anything -unless it is a harm to you' like a robot, like, and then you're like talking to them about something, I can't remember what it was, [ ], And then my social worker said 'ah what about this' [ ], but that's my information, that I'm sharing during my time with the counsellor. As much as I didn't like her, I tried to get on with her, [ ] but when things like that happen, it really doesn't help at all.* [Belle, Service User]

### *Accessibility and support*

Others welcomed the fact they could contact their psychiatrist or keyworker between their scheduled appointments:

> *If I had a problem she saw me within days. You know, I had the telephone number if I ever needed to ring [ ] so I would ring and make an appointment and I would be seen in the next day or as soon as she possibly could see me.* [Steve, Service User]

CAMHS staff were described as *'extremely helpful,'* as *'going the extra mile'* in providing care '*above and beyond'* what was required. This accessibility was not only important for service users but also for parents who felt included within the care plan for their child. The following quotes reflect a common perception of there being a *'direct line'* to CAMHS practitioners:

> *I can only sing CAMHS praises really. So you can see why it's [so difficult], from having such a good relationship and so supportive, and any time I phoned they were very*

*good and very prompt about coming back. [ ] They would have phoned me at home, if I phoned, and I remember she even phoned on her days off*. [Niamh, Parent]

*I think just knowing that they were there, and knowing that they were there for me definitely helped. Knowing that she could pick up the phone almost at any time and speak to (keyworker) was really important, and having a regular appointment.* [Suzanne, Parent]

However, other parent/carers felt isolated while supporting their son or daughter through their mental health problems. Some lost social contact with friends due to the time spent supporting their child, or to not wanting to talk to friends or family at a time when they felt their lives were so different. Peer support was recognised as valuable in this context and was something that they felt could be developed more within CAMHS:

*It would be very difficult and it would be very easy for parents to feel depressed. That's the bit of support that I think is missing in the CAMHS team approach, is where parents can talk to other parents and support each other.*

*it did feel good that someone else was there to (…) especially with being on my own here and not having (...) the support of (...) others, whenever you're feeling isolated and on your own and you think you're the only one out there dealing with it. The family are saying, "Just drag him down, just drag him down," and just do this and just do that, but someone else in the group is saying, "Yes, I've had that. Been there, done that." [*Margaret, Parent]

### *Relationships*

Relationships between users and staff in CAMHS were generally rated as another positive part of the CAMHS experience. Thus, practitioners were seen as non-judgemental, understanding, consistent, perceptive and trustworthy. Even though staff were regarded as challenging, young people felt listened to. For some this was experienced as friendship:

*(Keyworker 2) is a sweetheart, whereas (Keyworker1) was tougher. I adored them both, because, like I said, I would generally speak to them as if I was just having a chat to a friend. [ ] a bit of chit chat and that makes it easier for me to open up.* [Gabrielle, Service User R1]

*I would consider her a dear friend, really more. She is a professional but I wouldn't think of it as a formal thing at all. I was that comfortable with her, it was like going to meet a friend.* [Fiona, Service User R1]

*And I know that because, like I said, she can relate back to things that I had said weeks or maybe even a month before. So that's really reassuring that she is taking everything on board, which is definitely good. You know, if somebody, if I had say, brought up a point that I said before and they would, you know they would sort of be like, "I can't remember", I'd tell them but then if they done it again they'd be like, (you're not) taking me on. But she's definitely a great listener and knows her stuff, relates back to things, compares it to things that I've said currently in the session, so it's just very good.* [Eamon, Service User]

### *Authenticity of caring*

The experience of being listened to was closely linked to how young people (and parents) evaluated the quality of the relationship with practitioners and whether it could be described as *'real'* or authentic. Real care involved a personal connection, the willingness to *'go the extra mile,'* being accessible and available, respecting and meeting the person where they are at.

*They were real, they weren't all this bullshit, hugging and [ ]. Like, they weren't fake and you could tell they actually cared, because the one thing I said from the start, and I would have said this to them quite regularly, I was like 'Why do you care?' and they'd be like 'We do care', and I'm like, 'No, you get paid to care. There's a difference.' And they were like 'No, we do care.' And I'm like 'No, you get paid to care'. But these two actually cared and I just knew that. And they were real with me. They weren't fake, they weren't sticking to the book.* [Fiona, Service User]

Some of the more negative feedback on CAMHS experience was linked to the high changeover in keyworkers or psychiatrists. Service Users and parents were generally resigned to it but found it disruptive and unsettling.

*I think I was always nervous changing from psychologist to psychologist to psychologist because you obviously have to familiarise yourself with them and there are ones that you can't really connect with, it's harder to talk to them.* [Lisa, Service User R2]

*Every time I went in it was always just the same things that we talked about over and over, and I don't know, I'd like to think that I'm a wee bit more complex than just my school life.' [ ] I'm one of those people that finds it difficult to talk about stuff unless I'm asked about it.* [Sally, Service User R1]

Young people and parents were equally critical of the times when they did not feel listened to, whether this was communicated to them through the body language of the practitioner, the over-use of note taking in a session, or reflecting or feeding back inaccurate information to

them or others. Some participants reported that their request for a review of their medication was not listened to within CAMHS, or that they had no part in key decision-making:

> *Interviewer: And did you know anything about Beechcroft?*
>
> *Not one thing, I didn't even know that that place existed. And they just threw me in and that was it I had to go straight in that night, didn't give me a day or anything. I said can I go in the next day and they said, 'no, you're going up tonight, your bed's ready for you. We've already rung them' - they didn't even tell me they were ringing them*. [Roz, Service User]

### Parental involvement in CAMHS

Participants described the unexpected benefit that contact with CAMHS gave them to spend time with their parents, and the involvement of parents in their therapeutic journey was also raised as a positive part of the CAMHS experience. For some it became the space in which they could begin to deal with difficult intra-family issues related to identity or needs.

> *And just the fact that it helped me and my family to talk about it a wee bit more, because I never thought in a million years I'd tell them about anything like that.* [Sally, Service User]

For example, one participant undergoing treatment for gender dysphoria, said having his mum present in his meetings with KOI (Knowing Our Identity, the CAMHS Gender Identity Service,) provided her with insights into his gender identity, which might not otherwise have been possible to share with her. Parents reported similar experience. However, some participants felt that they would rather their parents had *not* been involved in CAMHS to such a great extent. One person indicated that he would like to have had a little more independence from his parents in advance of his transition to Adult Services. His keyworker concurred that Adult Services would suit him better as he is very independent. Other parents felt 'shut out' of contact by services – but their children, not services, requested this exclusion:

> *I always felt that there was so much that I wanted to say without Heather hearing. Maybe it's right, it's her they're dealing with and everything has to be out in the open, and that's really important, but I felt very lost and just didn't know who to turn to or what to do.* [Dawn, parent/carer]

In general, however, parents and carers were considered an integral part of the young person's initial help seeking and their remaining engaged with mental health services. Parents/carers were, predominantly, satisfied with the degree of their involvement and contact with CAMHS.

### *5.4.2 Expectations and experiences of adult mental health services*

#### Expectations of adult mental health services

In the first round of interviews Service Users were asked about their perception and expectations of adult mental health services. Some also touched on their perceptions of child and adolescent services and other non-statutory services. Practitioners from CAMHS suggested they believe Adult services view them as providing an overprotective and overly-indulgent service. Service user participants, who were particularly satisfied with CAMHS, felt that there would be no good time for the transition to Adult Services. One person likened the prospect of the move to *'pulling off a sticking plaster'* and several young people linked their resistance to change to an attachment with their respective keyworkers in CAMHS.

While CAMHS staff often resented the belief that they cossetted their patients, some staff participants reflected that this may be partially true, but, acknowledged in any case, that both services required a major improvement in mutual understanding

> *The two systems are quite different. I'd say in the adult system you might hear that we maybe overprotect young people and maybe see them too often, and don't prepare them for the reality when they're transferred to Adults.'* [CAMHS Practitioner]

> *I think we could probably learn a bit from each other in that whole tension around 'are we infantilising the kids too much?' [ ] … we could learn something, we could have more joint learning around that area.'* [CAMHS Practitioner]

While young Service Users tend not to hold such views about CAMHS, it was suggested by one Service User that CAMHS catered more for children with less serious issues and therefore was not appropriate for him:

> *CAMHS deal with everything, [ ] with people skiving off school to ADHD and autism and everything like that. I didn't really necessarily feel it was the right place for me [ ] I was more in the sense, I had a full blown adult mental illness, even though I was a teenager. [ ] to me it was CAMHS, it's for children [ ] they'll just think it's some kid coming up and making up stories.* [Steve, Service User, R1]

The perceptions and expectations of adult services ranged from the very positive to the highly negative, and everything in between. And while these expectations and perceptions were at times presented in a very vivid and colourful style, there was scant evidence that they were grounded in any formal factual source or experience. The lack of routine, professionally provided information and guidance about the structure and nature of adult services provision

contributed to expectations that are commonly skewed. We examine the implications these in a later section.

### *Perceptions of adult mental health services*

Transition into adult services, linked with the age of majority was anticipated by many of the young participants as a significant step into the adult world, and to opportunities, responsibilities, and risks, associated with that step. Some reported a greater readiness than others:

> *I can't wait! [Laughs] I can't wait. I really can't [ ] to be independent, to do everything myself. I don't know why you feel, you know at the age 17, 18, you just want to be independent, you don't want your mum and dad to do anything.* [Bradley, Service User R1]

The anticipated transition was also considered transformative in that Service Users expected adult services would provide more opportunities for autonomy, that it would make them *feel* different, more '*confident*,' *'feel older'* and that they would be *'better understood,'* and that they would acquire a better understanding '*of what's going on'.* Again, resonating with a perception that CAMHS was a kind of 'holding' service rather than interventionist, one participant expected AMHS would *'really want to get to the root of some of the problems.'*

### *Greater knowledge and expertise*

The expectation that their mental illness would be better understood in adult services underpinned a common perception that adult services, compared with CAMHS, was based on a more sophisticated, broader and expert knowledge base:

> *I just think that that their terminology and stuff will be a lot more advanced, which is completely fine with me.* [Eamon, Service User, R1]

This expectation is linked to a belief that they and their illness had outgrown child and adolescent services:

> *I guess I'm more of an adult illness even though I've had it for six years nearly. It wasn't just about teenage angst and depression, it was full blown ( ) rest of your life business. With AMHS, in a sense, it would be people with a lot more severe mental illnesses and in a sense that gives me hope for, in a sense, being understood a lot more than just someone trying to comprehend and nodding their head.* [Steve, Service User R1]

When conflicts arise with parents (or service user) regarding treatment in CAMHS, the move to adult services is seen as a resolution. For example, one parent expressed relief that her daughter was moving to AMHS, which she saw as an opportunity for her daughter to get the

'*right medication*.' While another mother said the staff in the CAMHS inpatient unit told her that *'there would be better services for him when he was 18.'*

### *Knowledge of adult services*

Service User participants highlighted the deficiencies in their knowledge about adult services, about its structure, and the interventions used. A commonly held perception was that they would receive less support than they needed. In the absence of good reliable information, young people created their own image of adult services.

> *I kind of presume with most people it's kind of CAMHS…three months… they're now on AMHS. And there's just a big nothingness in between. And I think myself, and a lot of people, would benefit if there was someone who kind of told them what to expect from AMHS, because people could have gone with high hopes or low expectations and it could be a big shock to them, or a big disappointment.* [Steve, Service User R1]

CAMHS clinicians also acknowledged the lack of factual information around the transition. In the following quote one keyworker describes her obvious uncertainty about systems and approaches within adult services. Moreover, it was commonly believed that patients would not receive the same level of therapy in adult services as they received within CAMHS:

> *Will they receive the same sort of input in adult services? I'm not so sure. Even in terms, if they're on medication, do they only get a medication review or will they also get therapeutic input [ ] It would probably do me no harm to know more about their systems, because I know that they have reorganised something in recent times. But then again we don't know which one they're going to be referred into.* [Michelle, Key Worker]

One parent described her anxieties about what to expect in Adult Services, and emphasised how the parents as well as the young people often experience such anxiety:

> *It was quite scary at that time, because you didn't know…I had experience through family members with Adult Mental Health and you knew things just maybe weren't going to be as…holistic as you would have got at Beechcroft. That was quite scary. And at that stage we didn't even get to know who she was going to be working with until the last minute. We didn't find out what was happening or get down to…I think it was two weeks before we actually got brought down to adult services to see the building and where she was going to be. It was quite an anxious time for parents and for the young people, too.* [Ruth's mother]

### *5.4.3 Relationships and personal connections*

While young people commonly described the relationship with the CAMHS keyworker as providing them a sense of security and trust, the anticipated relationship with AMHS staff was often a source of anxiety. Parents and CAMHS keyworkers sometimes echoed concerns about forming a new relationship with keyworkers and psychiatrists in adult services.

> *If I'm talking to (CAMHS Key Worker), and I'm like 'Simon's being a real dick' she knows who I'm talking about straightaway, even if I haven't mentioned it. But then if you're with someone new, from my experience: 'Oh my God, Simon's being a real dick' 'Okay, who's Simon? What's your last experience with him? How has your history with Simon been?' At that point it's kind of like it's dragged out too much, whereas it's more helpful to get straight in and say how I feel. I know there's nothing you can do to avoid that and over time it will be easier, but that's probably my main worry.* [Sarah, Service User R1]

Acknowledging that it would take time to build new relationships, service users worried about having to repeat their story as part of this process. In some cases, keyworkers felt that their patients wouldn't '*form a rapport'* in AMHS and would subsequently disengage. To illustrate, the following quote is from a person who had formed a strong relationships with her CAMHS keyworkers:

> *I was very, very upset about it. I remember the last appointment I ever had with them, [ ] she brought back (CAMHS keyworker) for me because I hadn't seen her because she had been off, and we just chatted and we all cried. I don't cry in front of people but I bawled like a baby, I was so upset for leaving them and I was terrified to be going into this new system…* [Fiona, Service User R1]

The quote from Karen, below, reflects a similar feeling of sadness experienced as she left the care of CAMHS and entered into Adult Services:

> *It's sad; it's hard a bit. I loved going over and seeing them and all and talking to them, I feel a bit let off a leash now. Now there is not that support there and you're just out there now, you're just let off your leash and you're kind of like "help", do you know what I mean?* [Karen, Service User R1]

#### Resources and availability of support

Adult services are perceived as '*busier*', with longer '*waiting lists'* and appointments short and infrequent. Such perceptions are based on information gleaned from friends, parents or their CAMHS keyworker.

> *I'm worried about what my new team is going to look like and I'm also worried about how often I'm going to get to see them, because I've heard from other people that have transferred over to adult services that the amount of time that you see your counsellor decreases quite a lot, and I suppose that's, as usual, a resource strain, sort of thing. But that would be my main worry about it.* [Sarah R1]

Others strongly associate adult services with medication. In the following quote, Sally, hinting at wider family issues, was wary of the perceived emphasis on medication:

> *That's the one thing I'm iffy about going into adult services, because I've been told really that I'm probably going to be put on medication which I think my mum would murder someone [for] [Laughs].* [Sally, Service User R1]

### *5.4.4 Moving on: barriers and facilitators to the transition process*

This section addresses the actual transition process from CAMHS to Adult Services, as described by the service users, parents/carers, keyworkers, other members of staff within statutory services and members of the community and voluntary sector. Six sub-themes emerge:

- Conflicting transitions/life events
- Developmental readiness for transitions
- The experience of the transition
- Preparation for transition
- Information provision
- Stigma

#### Conflicting transitions/life events

Turning 18 years of age, for many young people, brings with it other transitions, such as leaving school, moving out of home, forming sexual relationships, and progressing to work or university. Significantly too, these changes are usually accompanied by strong feelings of independence and a need for autonomy. It is often a challenging time for young people, irrespective of whether they are experiencing problems with their mental health or not. Coinciding life events can add another dimension to the difficulties around the time of transition. Speaking generally about the transition between CAMHS and AMHS, a manager from a community and voluntary organisation described these conflicting life events and complexities, in terms of how they often have to act as an intermediary between the young people and AMHS around the time of transition, to promote engagement with statutory services:

> *…they still are young people, really young people, trying to get into an adult world, but with the complexity of all those needs, maybe out of home, young parents, maybe a background of drug and alcohol issues and trying to access services and not have family support or parental support. [ ] We've often found ourselves the only agency linked in and having to really bang on doors.* [Manager of community and voluntary sector organisation]

Interviews with our core group of service users and their parents/carers and keyworkers also identified how the young people experienced major conflicting life events around the time of their transition from CAMHS to AMHS. For example, one participant was leaving home and entering university at the time of transition. In the following quote her keyworker reflected on these life changes and her coinciding transition.

> *At the minute there's been so much change for Gabrielle. She has gone to university and she had quite a busy summer and there were quite a few things happening, and you can see, if we had her list of appointments, you can see where she has started to disengage a little bit from us.* [CAMHS keyworker]

One of the multidisciplinary focus groups also noted the conflicting life events during the transition:

> *Maybe university aspirations haven't worked out for them. Quite a number of those don't manage to get through that first year and end up back at home. And emerging illness at that age, drugs and alcohol at that age.* [AMHS Clinician 2 - Multidisciplinary focus groups members]

> *It's a highly stressful time of life. In Learning Disability, where they've lost their school placement at 19 they're very much concerned and worried and afraid about what they're going to do next. Their activities have gone and the structure they were used to in life has gone, so people do get very unsettled. At 19, 20 there is a peak in referrals*. [AMHS Clinician 1]

Some of the CAMHS staff indicated that they were permitted some discretionary control over the timing of transition process. If they felt that another six months of care from CAMHS would lead to a discharge to the young person's GP, the keyworker might prolong the transition accordingly.

### *Developmental readiness for transition*

A consistent theme among parents and CAMHS staff relates to how service users might not have been developmentally ready for the move. Although 18 years of age at the time of

transition, some were considered emotionally and intellectually immature, requiring different, more intense care than that provided in Adult services. Many participants talked at length about the substantial difference a day makes, in terms of how a young person is treated when they turn eighteen years. A member of the community and voluntary sector reflected on how some young people struggle with this: *"Just because, suddenly we're 18, we're just supposed to have adult mentality."* Practitioners in statutory services also acknowledged the 'leap' experienced by young people making the transition at the age of 18. One CAMHS practitioner spoke about how they felt that society has changed in its outlook towards young people in the last decade:

> *Society has changed, when you reached eighteen, ten years ago, you were seen as independent. Now young people are viewed as a child through to their early 20s. [ ] Parental expectations have changed but services haven't changed. It's a big scary step for them, even with preparation.* [CAMHS practitioner, Multidisciplinary focus group]

One parent, particularly concerned about her son who had been an inpatient in a CAMHS unit for most of his teenage years, felt that there was a major disparity between his actual age and his mental age:

> *I think there's a real big gap in that age bracket 16 to 25; He's not mentally 18. Because he was in hospital for a year and a half, he's kind of stuck, and mentally he's about 15 or 16, some of his behaviours and that silly carry on...* [Eva, Parent/Carer]

Another mother felt that her daughter had missed out on her teenage years, and was therefore put in an unfair position when she was discharged prior to her 18th birthday with the expectation that she would fit back into life outside of the inpatient *'bubble'*. Some service users felt infantilized by their mental health problems, and were concerned that a much higher level of adult behaviour and responsibility would be expected of them as they transitioned to adult services, For example, Christine said, in relation to her anxiety symptoms:

> *I've only turned 18, I know I'm meant to be an adult and all that but since I've had my anxiety I feel that I have fell back till I was 15 again. Even though I'm 18 I feel like a wee 'un [child] that needs help and stuff, and then going to an adult service, they're going to be expecting me to be able to go out and to do things because I'm 18.* [Service User R1]

### The experience of transition

*It's not the transition that is the problem, it's what they find when they get there*. [Adam, AMHS Psychiatrist]

### *Service users' experiences of transition*

We were also interested in how young people and their families experienced the transition process. Several service users described feeling a sense of being rejected or pushed aside by CAMHS, feeling that they were no longer wanted by CAMHS or their CAMHS keyworkers.

> *You felt like you were getting pushed aside because you're not well or you're getting put to someone else, and you feel like that was too much to deal with. You're talking to someone about the way you feel, you're seeing your psychiatrist about your medication and then they're saying, 'we need to transfer you over' and it was just the whole impact of me talking to them about quite a lot of stuff and then they're like, 'we need to stop the brakes here and get you transferred over', sort of putting me on hold.* [Brian, Service User R1]

Participants from the community and voluntary sectors confirmed this sense of rejection at the time of transition. Again, the importance of building trusting relationships as a lengthy and sensitive process is very well illustrated:

> *One of my girls had the same worker for a number of years in CAMHS and the thought of him changing was so scary for her. "I poured my heart and soul out to this person and now I'm just being moved on," and it was that feeling of rejection …and being left and having to start from scratch. "I'm going to have to go through everything it took me years to say, to say to someone else, to start all over again.* [Key worker in a community and voluntary organization]

Additionally, some service users described their anxiety and fear of moving to Adult Services. A concern that is revealed in the next quote highlights a universal concern of repeating painful histories to a new set of 'actors' in the care system.

> *It was scary, I have to admit it was scary… …I just didn't feel very sure about it because I was scared in case I had to go in and talk to him about everything over and over again and bandage up old wounds and let them all out.* [Brian, Service User R1]

Echoing findings from previous research (Day, 2007), there was a definite element of our cohort who found the prospect of the move to AMHS to be 'scary.' Members of a community and voluntary group discussed the emotions of fear and rejection among young people that they worked with:

> *Melissa: One of my girls had the same worker for a number of years in CAMHS and the thought of him changing was so scary for her. "I poured my heart and soul out to this person and now I'm just being moved on," and it was that feeling of –*

*Jacqui: Rejection –*

*Melissa: And being left and having to start from scratch. "I'm going to have to go through everything it took me years to say, to say to someone else, to start all over again."* [Youth workers in a community and voluntary group]

Focus group participants described their fear around attending their psychiatrist in AMHS for the first time:

*I had to first go up to [Psychiatric ward], I was shitting myself, because that's where my psychiatrist was based, she was actually in the inpatient ward, the upper half it. [Adult psychiatric hospital], so it was a bit scary, because you could see all the inpatients.* [Member of community and voluntary group]

One person, later diagnosed with an eating disorder, experienced considerable problems between appointments in CAMHS and AMHS during her transition:

*...it was scary. I wasn't seeing anyone. I didn't know what to do. Making myself sick got really bad during those three weeks because I had no-one to talk to.* [Ruth, Service User, R1]

She found herself searching the Internet, 'googling' her symptoms in the hope of being able to diagnose her own health problems:

*It's like being blind, no that sounds terrible but it is, it's like walking in the darkness, you just don't know, you don't have a clue what's going on, nobody will tell you anything. It's like walking in the dark, it's a scary thing, I don't like it.* [Fiona, Service User R1]

Most service users anticipated the move to adult services in negative terms. Notable exceptions to this included the two transgender young people interviewed, who imagined that on turning eighteen and entering Adult Services progress could start to be made regarding their sex change. Both participants suggested that they were happy to be making the transition to Adult Services, because they felt it would give them more control of medical treatment and care. However, during his second interview, one person suggested that the process of his transition from female to male was happening more slowly than he would like, and was frustrated by this. More optimistic views emerged from people who felt that they had outgrown CAMHS or who had not developed a good relationship with her keyworker.

*I don't really have concerns with leaving CAMHS. I understand that people would have concerns leaving CAMHS because they get really attached to their counsellor and*

> *they're like "oh, what if I'm not able to talk to the next one? It's not going to be the same," and I just haven't had that experience. But I'm kind of hoping that I'll get a counsellor that I do click with and that can help.* [Sally, Service User R1]

Another person, more relaxed about the transition was at considerable pains to declare that his mental health problems were much more *'complex'* and *'unusual'*. He had a sense that AMHS would therefore be better equipped to deal with his 'more complicated' needs.

### *Parents' experiences of transition*

Parents also described their emotions at the time of the transition, including feelings of anxiety, concern, fear and sadness. However, there were some discrete differences between parents and children, with certain carers also showing a sense of frustration, helplessness and impatience. One parent described how her son fed off her anxieties around the transition to AMHS:

> *Well, because I don't know anything about it, you're a duck out of water, I don't know what's meant to be done or what, but it was really isolating and scary. He feeds off me as well, he knows when I'm anxious.* [Eva, parent/carer]

Commonly parents/carers were concerned about being excluded in the decision-making process about care and/or being left uninformed. The fact that family therapy was no longer available after the transition to Adult Services added to parental anxiety. For some parents this sense of exclusion represented a loss of role in their children's recovery pathway:

> *I think my mum and dad got more worried and weary and pointing stuff out more, and sometimes having scenarios in their heads that wasn't even happening, because they were so worried.* [Ruth, Service User R2]

The lack of advanced information about AMHS added to the anxiety, with several parents stating that they knew little about adult service provision. For example, one parent whose daughter had spent a considerable time in Beechcroft prior to the transition, was extremely concerned about her safety.

> *I can't even start to visualize it because it's too upsetting that she will be transferred to [psychiatric hospital] or [AMHS unit] or somewhere, [ ] I can't even get my head around that.* [Dawn, parent/carer]

Some parents regarded the transition to AMHS as a turning point. One described her attendance on transition training, provided by a voluntary sector organisation, as giving her welcome reassurance that her son would no longer be solely her responsibility once he had turned 18.

> *… there was transition training up in CAMHS run by CAUSE. So I went to that. But there wasn't really very much, you were made aware through that, that once he turned 18 (...) technically he wouldn't be my responsibility anymore, which in a way, is kind of a relief, because you are responsible, you're still responsible, but for me the thought of thinking someone else is going to help and take some of this responsibility was a big relief.* [Eva, Harry's mother]

Diagnosed with a psychotic illness, her son spent most of his time in CAMHS as an inpatient in Beechcroft. However, since making the transition to Adult Services, service provision appears to have been inadequate, and he resided in a hostel temporarily before being admitted to an adult inpatient ward. Others expressed similar views about the need for safety.

> *Now she's been back in for a very long time, and I agree with their decisions to have her detained, because I don't see that there's any other option, but then you become used to that and I walk away now thinking 'right, she's okay there, she's got all those nurses and they're all lovely, the doctors will come to see her every Monday,' [ ] and that feels very, very safe and I know that. That's a good feeling. It's horrific, it's horrendous, it's awful to look at, but it's safe, so I have become institutionalised too.* [Dawn, Heather's mother]

### Preparation for transition

> *Nobody knows at the minute at CAMHS who my new team is going to be, which is quite hard to get information out of. It's quite hard to find out, they don't know if it is going to be male or female, they don't know how old they're going to be, and that's actually really important for me.* [Gabrielle, Service User R1]

#### *Views of service users and staff*

Staff consistently stated that even when the service users felt that CAMHS had done a lot of preparation, the transition remained a 'step into the unknown'. Few service users were offered jointly-attended meetings with their CAMHS and new AMHS keyworkers. Those who were, benefited from this approach, making the transition process *"a wee bit easier",* as one person described it.

In many cases, part of the preparation for transition involved a deliberate incremental reduction in the amount of support offered, such as the frequency of appointments - as a preparation for limited engagement with AMHS post-transition. However, community and voluntary sector staff argued that young people using their services were generally ill prepared for the transition.

> *There is no preparation for how the two services operate so differently [ ] that's when we're really challenged, because we find that we are filling in the gaps and the young people are phoning us in crisis and phoning us whenever they're feeling low or suicidal or self-harming, because we're the people that have the relationship with them [ ] they still are young people, really young people, trying to get into an adult world.*

According to many of the young participants, the gap between successive appointments with CAMHS and Adult Services was reported as one of the worst aspects of the transition process. In some cases, the young person was left for a few months without being seen by either service, when they had perhaps been accustomed to meeting with their CAMHS keyworker on a weekly basis prior to the transition. One person said:

> *After being used to seeing someone nearly twice a week sometimes for a few years and then just going without anyone for a few months, it was kind of like a shock to the system without the support being there.* [Lisa, Service User R2]

Some practitioners discussed the provision of parallel or overlapping care, during which the young person is seen for a certain period by both CAMHS and AMHS. Although this was suggested as being a commonly occurring process, only one of the service users identified having experienced a period of parallel care. There was no consensus about the value of joint meetings - some practitioners argued that it was only required by the 'more anxious' young people while others were concerned about the logistics needed to facilitate joint appointments, particularly in more rural Trusts where facilities can be quite far apart geographically.

Only one service user reported receiving more than one joint appointment; she found the process beneficial:

> *Int: So the adult social worker came into your appointments with your previous...*
>
> *Yeah, with my CAMHS worker, so she came into a few of those just to kind of get a lay of the land. So that was good, because I would have been so much more nervous then going to meet her for the first time, not knowing what she looked like or anything.* [Gabrielle, Service User R2]

She described having her CAMHS keyworker present for these first meetings as being '*an absorber of awkwardness'.* Interestingly, the new AMHS keyworker also used this adjective to describe this first joint meeting:

> *Yes, and it was a bit awkward, I suppose, having an appointment with an extra person there and, I suppose, for me, you do feel a bit like a gooseberry nearly, because they're the ones doing what I would normally do, but it was good.*[Shirley, AMHS keyworker]

Another service user (interviewed at time 1), identified a joint meeting as being the main factor that could ease the transition process for her:

> *Interviewer: So is there anything that you feel needs to happen before you feel able to make the move?*
>
> *I think meet the new keyworker with (CAMHS keyworker). I would want her to be there just because (...) I wouldn't feel alone. It wouldn't be as daunting, I don't think. That's the only main thing.* [Clara, Service User R1]

### Information provision

Apart from parallel care and joint meetings, service users were sometimes prepared for the transition to AMHS more informally. Thus, some had discussions with their CAMHS keyworkers involving the transfer of information about what to expect in Adult Services, for example. However, most people felt that the information provided was inadequate. Some of the young people commented on the lack of written information provided to them pre-transition about what to expect from Adult Services. Service users and parents didn't always remember what they had been told verbally about the change in services:

> *Interviewer: what kind of information did you get?*
>
> *They probably did give us information; in fairness they probably did. I don't actually remember any of it, but I would put that down to me.*
>
> *Interviewer: It was verbal, as opposed to anything written?*
>
> *Ah-ha. They told you the emergency contacts and stuff, and to be honest, I can't even remember. Isn't that awful?* [Fiona's parent/carer]

Other service users felt that CAMHS had not provided them with the kind of information that they would have benefitted from knowing, verbally or otherwise, about the services that would be offered to them following the transition to AMHS. One of the service users, stated:

> *I don't really know what's in store for me when I go to adult services, nobody really explained it all that well.*
>
> *I thought maybe she [keyworker] didn't know much about what adult services was going to be like. But really, all she said to me about adult services is that they'll probably put me on medication, and that's really all she said to me.* [Sally, service user R1]
>
> *I don't have a clue, really. Don't know what I'm stepping into, hopefully it's like CAMHS anyways.* [Karen, Service User, R1]

However, with regard to the last quote, the participant gave the impression in her interview that she not interested in knowing anything more:

> *No, I'm just kind of like "whatever." [laughs] I'm just kind of like... They're just telling me these things and I'm just sitting there...that's all right then, I have to do it anyways so I just wasn't even bothered to ask them, I was just "oh, that's all right, like".* [Karen, Service User R1]

Commonly, service users believed that the transition was an inevitable consequence of turning age 18, a belief that engendered a considerable degree of fatalism. In fact, some service users would rather not know about the practical impacts of the transition and others appeared to be in denial about the eventual transition. One keyworker, said that, *"[Christine] would kind of joke and say "look, can we not just pretend that I'm still 17, it's only a number and why does a number have to change things?" "* When Christina herself was asked what she knew about adult services she stated, *"I don't really bother talking about it, I don't want to talk about it."* Similarly, Gabrielle, who likened the move from CAMHS to AMHS to *"ripping off a sticking plaster",* indicated in her interview that she was not the kind of person who wanted to hear a lot of information.

### Stigma and adult services

We noted commonly held perceptions of adult services as a '*stricter' 'colder'* environment, described as *'dark,' 'gloomy,' 'dull'* '*not a nice place'*, where the clinicians were rushed, under pressure and under resourced, and where a children's play *'apparatus'* and '*nice colourful sofas'* in the waiting room, would be replaced by a '*water cooler'* and a TV in the corner showing dull adult television entertainment such as *'Homes under the Hammer*.'

Adult services appear to be much more stigmatised and therefore, stigmatising than CAMHS and this deterred a full engagement with services. One participant described how he would be much more guarded about telling friends he was going to an AMHS appointment, principally because of its location in the main adult psychiatric hospital. The close proximity of outpatient to inpatient was a concern to him and he suggested that he may in fact not *'say so much'* to the psychiatrist in case they decided to keep him *'in for examination*.' One participant described the prospect of going for his first appointment as *'nerve wrecking*.' He told us he had *'heard things about it'* that made him *'nervous.*' The fear of being admitted to an inpatient ward, the fear of how his friends might view him and the fear of being regarded by staff and clinicians as *'dangerous',* contributed to this young man's anxiety about his forthcoming move to adult services. It also influenced his thoughts on how honest he might be with his psychiatrist:

> *That there are people in there that can't have shoelaces on their shoes, or there are people in a room with nothing that could be a danger to them. [ ] it's a place for people who are mentally ill [ ] (who are) too dangerous to themselves [ ] or to be out in public, whereas I'm perfectly sane and perfectly normal. [ ] I know I'm just going there for a routine check-up on how I'm feeling, but just the fact that they're only a few walls away or something like that [ ] I don't want to walk into a room and there's going to be something spongy or something that makes you feel that you're going to be dangerous. Say the glass is really strong and you can't actually physically contact the person in reception, you can just see them [ ] because in CAMHS it was just more friendly.* [Ian, Service User]

One mother touched on something similar. Her son made the transition to adult services while a patient in Beechcroft. He was discharged home with care from the community mental health team when he turned eighteen. She questioned whether her son pretended to be better than he really was in order to avoid a move to the adult inpatient hospital:

> *Well our options at the time [ ] coming up to him turning 18, our options were 'Named Adult Acute Inpatient Unit' or home. But there was no middle ground it seemed. The thought of him going into 'Named Adult Acute Inpatient Unit' really scared him. There's a stigma, I mean it's based down at 'Named Adult Psychiatric Hospital', and he was so petrified. So I don't know if that was spurring him on to be well…or to act well. I don't know.* [Eva, Parent]

### *5.4.5 Adapting to change: Post-transition experience (Experience of AMHS)*

This section will address experiences of Adult Mental Health Services (AMHS), post-transition from CAMHS, as told by the service users, keyworkers, parents/carers and members of the community and voluntary sector. Four sub-themes emerge:

- Critical/problematic experience of AMHS
- Positive experience of AMHS
- Differences between CAMHS and AMHS
- Diagnosis and treatment

#### Critical/problematic experience of AMHS

Most service users, interviewed after the transition, identified aspects of Adult Services that they found problematic. Reflecting on their experiences in CAMHS, they drew unfavourable comparisons between the services offered to them pre- and post-transition. The most frequently mentioned differences between the services related to frequency of appointments.

Several of the service users, still found this element of the transition to be quite a shock however:

> *When I was in CAMHS if I was struggling I was like "right, I've only got three more days until I see someone" [ ] but now you don't have any idea when you're going to see someone until you get a letter through the door. The most they see people, from what I'm aware of, is once a month, which I think is pretty appalling, really, because there are people out there, including myself, who would need a lot of extra help, who need to be seen more than once a month; they're just not well enough to be on their own.* [Fiona, Service User R2]

Another participant described how appointments within Adult Services tended to be shorter as well as less frequent:

> *My last appointment with my psychiatrist a couple of weeks ago, he was ten minutes late and took me for eleven minutes, and in CAMHS they would take me for at least an hour every three or four weeks. So it's a massive reduction in the services I'm offered.* [Paul, Service User R2]

However, he also felt unsupported by staff in Adult Services and that he was dealing with his mental health problems without their assistance. Another of the service users was highly dissatisfied with services from AMHS, not least the infrequency of appointments with her psychiatrist in Adult services. Jennifer, who had primarily been treated for an eating disorder, as well as depression and self-harm, desperate for increased appointments with staff in Adult Services post-transition, threatened to re-engage in her disordered eating behaviours.

> *Actually a funny story. I thought a few months ago that my Adult Services weren't paying attention to me and I thought that if I began to lose weight they would pay more attention to me and I would get appointments and get talked to about, not just eating disorders but about what I was really going through. Since then, up until recently, I do have a keyworker that I would see more often. It would probably be every two to three weeks, and I just recently opened up to her about it. It's not a really big problem.* [Jennifer, Service User R2]

The other side of the coin is that Adult Services appear to lack the resources to enable them to see young people as frequently as they are seen in CAMHS. This comment, from a clinician in AMHS, reflects that part of the culture in Adult Services is to allow the young people to learn how to cope more on their own and rely more on the internal resources that they have been equipped with.

> *Yes, that's the bit sometimes where families can get anxious [ ] "Will you see them every week and why are you not seeing them every week?" and we say; "We don't really need to because they've got the resources and we're trying to help and we'll be here if there's a true crisis" [ ] and they're spreading their wings.* [AMHS Clinician, Multidisciplinary Focus Group]

*One participant with a diagnosis of a personality disorder, stated that he felt that there was not sufficient support for him and his family in dealing with his mental illness. He had been able to cope with the full school week while in the care of CAMHS, but was now obliged to reduce his hours in school, which he attributed to the lack of support he was receiving from Adult Services. Another service user, felt that, "*With the adult services, there's less of a support system, it's more of an emergency system."

A recurring theme among participants was that the approach of practitioners in AMHS was considerably more *'formal'* than that in CAMHS, generally regarded as "off-putting". Jennifer stated, *"it was just so formal within AMHS Facility. It's the only word I could describe…formal…it's not relaxed."* Some individuals had more specific problems with their new keyworkers or Consultants in AMHS, and felt disregarded or patronised:

> *I personally don't get on with him, but someone else might love him. I don't really get on with him. I don't think he's helped me in any way, he hasn't taken on board anything that I've said, anything that I've said, he's argued with, not physically argued but he said "No", or "We can't do that because..." … So no, I wouldn't say that he's helped me*. [Fiona, Service User R2]

Jennifer, who at the time of her interview had been attending Adult Services for over a year, depicted a sense that she had yet to develop a relationship of any significance or worth with her AMHS psychiatrist. This was partly attributable to the infrequency with which she would see her psychiatrist, and she reported how:

> *"Up until a few months back I couldn't even pronounce his name, I wasn't seeing him and he was introducing himself to me every time"*
>
> *It's not a situation where you walk in and you sit down and they go right "how have you been? You were like that last time I saw you," blah blah blah. It's sit down, read about them first and then pretend that you know them, you know their mental health, when really they're just reading it off a book. [ ] It just feels detached. It doesn't feel like a personal healthcare service.*

### Positive experience of AMHS

Thus far, a very negative picture has been painted of service users' experiences of AMHS, but it should be noted that the feedback was not exclusively critical. Indeed some of the young people appeared to thrive under the care of Adult Services, and reported highly positive experiences. While, as reported in the previous section, quite a significant proportion of service users described problematic relationships with staff in Adult Services, there were a number of other young people who developed relationships with their AMHS keyworkers that were equally, if not more, satisfying than the bonds they had previously established with practitioners in CAMHS.

Ruth, a service user who had been an inpatient in Beechcroft for a significant period of her teenage life due to her disordered eating, reflected positively on her experience of AMHS. While she had developed close bonds with some of the staff in CAMHS, she also painted a positive image of the care she had received in Adult Services.

> *I wouldn't have preferred any therapist over the other. I have a good relationship with all of them. Well, my relationship with (CAMHS Nurse) might have been a wee bit better because she was with me in-patient and outpatient, because she was a nurse on the ward. So maybe she knows me better than all of them, but I get along with them all equally.* [Ruth, Service User R2]

> *I haven't ever come in contact with anyone, either at CAMHS or Adult Services, that I have been at all dissatisfied with, like a staff member, they've all been really, really, they've all cared, they've all really cared.* [Gabrielle, Service User R2]

There were a few service users who reported very positive feedback on the relationships they had established with practitioners in AMHS. One felt that AMHS provided a more confidential service. She had been the victim of a sexual assault but had not disclosed this information to any of the staff in CAMHS as she felt that it would get back to her parents. However, in Adult Services she felt that she could be open about this highly traumatic experience, safe in the knowledge that it would not be fed back to her parents. Another described her AMHS keyworker as, *'very helpful, very supportive and very friendly.'* She had been having problems coming to terms with her sexuality, and felt that staff in CAMHS had been dismissive of these concerns; however with her keyworker in Adult Services she felt that her concerns were taken seriously and that her problems were rationalized for her. She was happy to be discharged following six or seven sessions with her keyworker in AMHS, after which they were both satisfied that she had made sufficient progress. Young people who developed positive relationships with their keyworkers in Adult Services generally tended to report an improvement in their mental health while in the care of AMHS. Thus, Lisa has found the

guidance she received in Adult Services to be a lot more *'concrete'* than in CAMHS, and feels that her transition marked a turning point in terms of an improvement in her mental health:

> *I think changing to AMHS has just been a lot better, because I know that even though I am still on medication and I still have those small problems that I actually know what's wrong, because it has been figured out and told to me instead of me just flitting from one problem to another and thinking maybe it's this or maybe it's that. Yeah, it was more concrete for me and it felt a lot more stable going there, so it definitely improved me, I guess, in a way.* [Lisa, Service User R2]

Another participant described how her depression had lifted dramatically following her transition from CAMHS. In regard to progress with her mental health post-transition, Ruth stated, *"It's made me mature. My recovery's moved along."* Others reported similar progress when they moved to adult services:

> *I felt like I was at a standstill in CAMHS and it feels now, and I've only been with the Adult Services for a couple of months but I feel like I've made so much progress.* [Sally, Service User R2]

> *…my life was at a standstill and when I joined CAMHS it helped a tiny bit. But, like I said there's reasons why it wasn't best suited to me. Then when I went to adult services, it opened my eyes a bit, and the ball has started to roll now and I'm finally getting my life back on track and doing things that a normal person should do. So it's just, that's personally for me. I really enjoy it, it's very helpful, it's opened my eyes, getting my life back on track and just overall happy.* [Eamon, Service User]

The range of feedback on experience of Adult Services in this section clearly portrays how individualistic these experiences were for the young people involved in the IMPACT study.

### Differences between CAMHS and AMHS

A number of differences between CAMHS and Adult Services were highlighted. A Clinical Psychologist in Adult Services, described how he felt that there was more of an 'open door' policy in CAMHS, and suggested that in CAMHS the staff seem to have the resources available to them to follow up patients who fail to attend their appointments. In Adult Services, there is a strict policy whereby if someone fails to attend two consecutive appointments, they are discharged and have to be re-referred by their GP. Adult Services place more onus on self-management and personal responsibility:

> *I'm not sure how much preparation CAMHS do, as I've never worked in it, but certainly it's a big step for people and it is different, because yes, if they come here and if they don't turn up for [ ] two DNAs and they're discharged and that's that. Then they will*

> *have to go through the whole referral process again. So yeah, I suppose it can be a difficult move.* [Joe, AMHS Key Worker]

Once a young person reaches the age of 18, there is no obligation for them to have their parents/carers involved in their health care, and the impact of this for both service users and parents/carers was explored. The change in levels of parental involvement provoked some conflicting reactions. Lisa, who was generally very positive about her experience with Adult Services, said *"…but I think when I got to AMHS I felt more prepared to go by myself."* Others missed the security of having their carer come along to appointments with them. A couple of service users referred to their forgetfulness; they didn't seem to trust themselves to remember things like future appointments and changes in medication:

> *It's a lot different, because when you're in CAMHS they run everything by your mum [ ] they would have told your mum appointments and medication differences, but here they have to ask you if you want your mum or dad or your guardian involved, if we're allowing them to, which is a big difference, because normally they just did it. It's quite nice, actually, to have that independence but, at the end of the day, I think that I'd rather have it the other way, because I forget things. It's awful. I forget to tell my mum appointments. Medication changes, I always get them to tell her because I can't remember things like that, and I really should be, I'm an adult now.* [Fiona, Service User R2]

We found several cases where the young person desired adult independence but in reality they still needed parental support, emotionally and practically. In general, most young participants said that they were still happy to discuss their mental health care with their parent/carer following the transition. Levels of parental involvement in the service users' care, particularly following their transition to Adult Services, were variable and quite individualistic. For the majority of young people, however, it seemed that their parents/carers were less involved following the transition. Steve depicted a perspective on this when he said:

> *Once you turn 18 they don't care if your parents are dead or still alive, they're not going to tell your parent*s [Steve, Service User R2]

This seemed to be quite an extreme portrayal of how Adult Services tend to regard parent/carer involvement, but it was a sentiment that came up quite frequently. From the parent/carer perspective, one mother expected a similar outcome in terms of parental involvement post-transition:

> *Interviewer: And what about now with the adult services and the staff?"*

> *Well it's like overnight, ta-ra, "you're an adult; get on with it." That's what happened.* [Eva, parent/carer]

This was an experience reflected by several parents and service users in terms of making the transition to Adult Services. With some exceptions, most parents described being excluded from their son/daughter's care /treatment plan post-transition and found this a difficult aspect of the transition. One person, for example, complained that her parents, who had been heavily involved in her care while she was in CAMHS, had not been mentioned, nor seen, by staff in Adult Services when she had been with them for more than a year.

> *They've never even been mentioned in appointments, like "Do you feel I should talk to your parents? Would you give me consent to update your parents on what's going on?" My mum's never met my doctor from adult services, and now I'm over 19 and have been there a year*. [Jennifer, Service User R2]

Others felt that the transition, in terms of parental involvement, was so dramatic that perhaps parents should be better prepared for their son/daughter's transition to AMHS:

> *The only thing I could think to change is coming towards the end, I think parents should be prepared for the fact that when they get to adults they're not going to be involved as much. I think parents need to be prepared for that, because at one appointment they're involved and the next they're not, and it's not fair. It was really daunting for my mum, she was like "Wait, I'm not coming in to this appointment?" And I was like "well, no". I think parents need to be prepared for like it's very much your recovery.* [Ruth, Service User R2]

However, some young people described how AMHS offered the option of whether or not they wanted their parent/carer to be involved in their care following their transition to adult services. Fiona described how it was good to be given that option, and to feel that sense of independence, but ultimately she would prefer to have her mum involved, as she was not ready for the responsibility of remembering about her appointment times and medication changes. Others reported a dependency on parental reminders about appointments that continued after the transition to AMHS. Our interviews suggest considerable variation among AMH services in the range of discretionary involvement permitted parents/carers.

> *My mum does all the liaisons with the appointments and stuff, she sorts all the times and my counsellors, and the (keyworker) will call my mum in between appointments to update her.* [Gabrielle, Service User R2]

*Adult services see me on my own once a month just to see how things are…which is brilliant, it is really good, really helpful.* [Beth, parent/carer]

### Diagnosis and treatment

Some of the other differences between CAMHS and Adult Services relate to: (a) the perceived availability of a wider range of medication in AMHS; (b) the tendency for interventions to be more goal driven in AMHS; (c) the lack of access to family therapy in AMHS; and (d) diagnosis in AMHS

### *5.4.6 Understandings of recovery*

*'Being able to do what you want to do without being stopped by your mental health, I think that's my definition of recovery, with a bow on it.'* [Gabrielle R2, Service User]

Recovery is a concept that is usually more associated with adult services than child and adolescent services. With the establishment of Recovery Colleges across the Health and Social Care Trusts the concept of recovery is becoming more familiar and developed within the mental health service.

Some young people in the IMPACT study envisaged receiving care and support from mental health services for many years or for life. Others estimated their contact as time and goal limited. Their outlook in this regard, and their conceptualisation of their own mental health problems, acted as a filter through which they both anticipated and experienced their transition to adult services. Blended into this mix was their understanding of recovery, and the part mental health services might play in their personal journey towards that recovery.

As well as analysing the responses young people gave to our direct question '*What does recovery mean to you*,' interview material on the nature of relationships with keyworkers, the role of family, carers, and other support networks, gave further insight into what they regarded as the essential components of this concept for them. Drawing on all of this material we consider how services, and particularly those provided to young people around the age of transition, might respond to the needs they express from a recovery perspective.

We posed this same question, i.e. the meaning of recovery, to carers and keyworkers, and their responses serve to highlight the convergence and dissonance expressed in relation to what might be regarded as this philosophical perspective.

### To be normal

Recovery and hopes for the future were intertwined in young people's thinking. For some aspirations of recovery were measured against the socially ascribed and received markers of *'normal'* life and living. These markers were characterised by the central motifs of economic

independence, (finding and keeping a job), parenthood, (setting up a family and home) and community engagement (shopping, socialising, pursuing hobbies and interests).

> *Get a job, I think everybody wants the same thing, a job, family, being able to do what you want to do, just kind of normal stuff.* [Christine, Service User]

One young transgender man included such markers in his deliberation of the meaning of recovery. As well as successfully moving through the treatment and surgery required to live as a man, he just wanted to *'get [himself] a job, just be myself, get married, and have kids, just the typical future.'*

One young man, who had a diagnosis of ASD and experienced depression, felt at the time of interview (prior to his transition to adult services) that he had essentially *recovered*. He felt he was *'calmer'* and *'happier'*, he had re-engaged with his friends, had got back into his hobbies, and felt *'safe'* to leave his home again. Being able to participate in 'routine' things and enjoy quality of life amounted to recovery for Ian. His account, and that of others, resonates with the idea of 'social recovery' where an individual can recover their lives without necessarily recovering from their illness. We were unable to interview Ian after his transition to adult services but understand that it was a transition that he found difficult.

The desire for happiness and contentment, for balance, to be calmer, more relaxed, and to appreciate day-to-day life, were sentiments expressed by many of the young people in the context of this particular question. Some linked these sentiments with '*normal'* living, *'an average normal life'*, *'doing just normal human things*' or as one young woman put it *'just living.'* Jennifer *'thought'* she had recovered from an eating disorder but experienced a *'set back' when [she] started adult services.'* The recovery journey is not one that young people commonly regard as straightforward or linear. Some like Jennifer, however, place it on a timeline. She drew on information or advice that suggested *'eating disorders take five years to recover from.'* Another young woman, Clara, felt that things will improve significantly for her after *one year* in adult services, while Steve expects to be in adult services '*for the rest of [his] life."* He believes that the *'normal'* will continue to elude him: *'I will never be my normal, everyday, how I should be.'* Likewise, Fiona, imagined needing adult services indefinitely, for support and medication.

Responding to the same question, Fiona, said it was something she had already been asked by her keyworker in CAMHS, to which she '*would always say, [recovery is] to be normal.*' She acknowledged that her answer required further unpacking, in that *'nobody is normal.'* The unpacking of the statement (outlined in the section below) led Fiona to conceptualise recovery

as the *absence* of all that characterised her mental health problems, and like Steve and a few others, she drew on a more traditional and medical model of illness and wellness.

### Recovery – the medical model

As noted above, some young people drew more directly on the tenets of a medical model of illness when thinking about recovery. When Fiona unpacked her definition of *'normal'* as an indicator of recovery, she described it as being *'out of my depression, 'out of my psychosis, [ ] not having these problems'*, '*being out of everything.*' Recovery was the absence of mental illness or mental health problems, and for her also meant being *out* of mental health services, though this was something she was not hopeful of.

For another young person, Belle, the indicator of recovery was the absence of self-harm in her life. And for another it was '*getting better'* and feeling more like her true self. Steve also drew on this model, suggesting that he did not see himself *'getting better'* and that he would never be *'one hundred percent.'*

### Recovery goals and outcomes

When Belle talked about recovery being the absence of self-harm in her life, she also suggested that getting help to stop self-harming was, for her, the main goal or desired outcome of her referral to CAMHS. Recovery for her was linked to a specific goal. The importance of setting or acknowledging goals and outcomes, emerged as an important component of the recovery journey for young people, and indeed of their engagement with services.

Belle felt that keyworkers side lined her main goal, as, from her perspective, the focus of the therapy became her family and relationships within the family. She wanted help to stop her self-harming behaviour and regarded the primary CAMHS' goal as too focussed on the more holistic goal of repairing the fractured family relationships. The perceived deviation from her personal goals led to Belle's decision to stop attending CAMHS:

> *…to be honest I had difficulties with self-harming, I wanted help to stop doing that, that was the whole reason I was referred to it in the first place and that was the reason why, what I wanted to get out of it was to stop doing that. But that wasn't focussed on, what was focussed on was the family situation and what was going on in the family, because they probably seen that as 'we'll fix this, and try and do something with the family which will help Belle and then she will stop doing this'(…) But that - didn't - really help, to be honest. When I say they didn't really focus on recovery, it was just "ok we'll check to make sure she's not self-harming", and ok "we'll talk about your mum, and we'll talk about your dad" we're not really talking about what is it that makes you feel like this, what is it that makes you feel, you know what you would expect them to be focussing on. But I don't know what sort of approach or model they were using, but they did their*

> *thing and it wasn't really focussed on what I needed to get out of it. [Belle, Service User]*

The absence of a clear goal or planned outcome from therapy, and particularly one with which young people identified, was something that a number of others named as problematic in their engagement with services. Young people, at school or college, are perhaps familiar with and work more effectively with goal orientated tasks and interventions, and respond more easily to the idea of recovery within this framework:

> *I don't think they really explain when you're going through your sessions and all what really is going to be the outcome at the end of it. I mean if you were told, after this many sessions you're going to be at this point, or this is what we aim to do, then you might be like OK, this might work out OK for me if I do actually do it, but there is none of that, it's just straight in, straight out*. [Roz, Service User]

Belle echoed these sentiments when she questioned whether or not *'there's enough push for recovery in CAMHS.'* She concluded from her own experience that indeed there wasn't, and that she doubted the concept of recovery *'was ever referred to'.* This issue was raised again in an interview with staff from a community organisation that support young people with housing, employment and mental health needs. Relaying the feedback they receive from their service users within mental health services, the staff reported how young people find the lack of an obvious plan or end goal problematic, with some reporting they were unsure why they were actually attending mental health services at all. A staff member told how young people complained to them:

> *There's no clear "you'll work with us until this is achieved or that's achieved", there's no kind of "you're progressing or you're not progressing", it's like a piece of string, how long you're involved in services and without a clear plan or direction or without a clear, "you're making progress."* [Jacqui, community worker]

Clear goals, direction, and markers of progress are elements of a recovery-orientated service sought by some of the young service user participants. For example, one young woman, who has been in adult services for a few years reflected on her journey towards, what she described herself as, recovery. While she said she now *'feels recovered'* she could not identify what necessarily brought her to this stage, as 'recovery' was not the focus of her experience within services. Rather, the emphasis within services appeared to be more associated with deficits - *'the bads, the negatives…looking at what went wrong'* and as a result she now finds it *'hard to point out what did help [her] to recover, "cos nobody else really pointed it out."* [Sadie, Service User]

### Agency and empowerment

From a recovery perspective the need for goals and clear outcomes within mental health services can also be understood in relation to agency and empowerment. A thread running through the narratives underlined how mental health problems and illness contributed to young people feeling *'out of control'* at some level. The concept of recovery was about regaining a sense of control over their lives and their mental health problems, particularly in relation to decision-making. Thus, regaining autonomy was central to how some framed their hopes for the future.

> *When you are in that state you don't feel in control, so you want to go to somebody, not that makes you feel in control, but gives you some sense that you will get some sort of control back.'* [Belle, Service User]

While acknowledging the limits of control or choice available, young people felt relatively uninvolved in the decisions about their care. For example, while they accepted that it was probably impossible to choose their keyworker, they talked about how a difficult relationship or poor connection with a clinician detracted from, or ruined the potential for, good therapeutic work or outcomes. Some felt that their views and wishes were not acknowledged or respected:

> *I found they led it instead of me - and also not giving you a choice about involving your parents and things like that in sessions.* [Belle, Service User]

Some also suggested 'attitude' and 'mindset' were important ingredients in the recovery journey. Brian talked about the need for a *'good active mindset'* to '*put your mind to it'* 'to be *'actively busy' 'to try to take your mind away from what's going on in your head.*' Others acknowledged the need for active self-management in getting well:

> *I think there will be a time where 'Fiona, you need to…not wise up', (…) it's hard to explain really what I'm trying to say, like it's not all down to them, I need to be doing stuff as well. I don't know what 'stuff' is. In terms of sleep I need to cut down on my caffeine ( ) and in terms of my depression ( ) I do need to push myself to just go and do it. Even if it's just having a shower, getting out of bed.* [Fiona, Service User]

The degree of personal agency, choice and control young people experienced as part of their engagement with mental health services was central to the relationships they developed with practitioners and clinicians, to their experience of the transition between services, and ultimately their perspective on recovery.

## 5.5 Stage 3 Findings Part 2: The role of relationships in transition

Part 2 analysis also has 6 sub-themes (see Figure 5.2) within the broader theme of relationships. These include the importance of the relationships in the delivery of mental health services, communication, bonding and connecting, equity and power, the role of carers, and other sources of support.

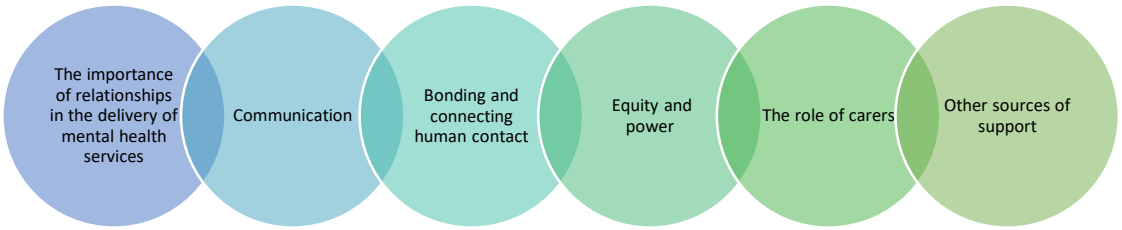



**Figure 5.2:** Part 2: Relationships

### *5.5.1 The importance of relationships in the delivery of mental health service for young people*

Within any paradigm of care or service the therapeutic relationship is central to the patient experience (Sosnowska et al., 2013). All treatment and interventions are mediated through and with other people - clinicians, keyworkers, clinic staff, peers and family.

When talking about their experience of CAMHS and AMHS, and of the transition between the two, young people highlighted the centrality of these relationships and were most vocal in their evaluations (from both a positive and negative perspective) of those with keyworkers and psychiatrists. These relationships were experienced within the context of what was happening for the young person at the time and, as highlighted in the quote below, were, for some, integral to their experience and understanding of recovery. One young service user with experience of both CAMHS and adult services was asked by the interviewer how important relationships with keyworkers were:

> *To have a keyworker that cares is literally…it means so much. To have a keyworker who you don't bond with or don't get on with, you're not going to want to recover, whereas my keyworker, we got on like a house on fire, our personalities were so similar and really easy to talk to. I think it's important, and I think it's important for people to say if they don't bond well with their worker, to ask for a change. That shouldn't be anything someone's ashamed of, because there were a lot of people who were like "I don't get on with my keyworker, could I please change it?" And I think people should be able to say that, because when you don't have a good relationship you don't want to go to recovery sessions. So, I think good relationships*

> *are actually the key to recovering, because you can't recover on your own and you can't recover with someone who you don't get along with, it needs to be someone you bond with.* [Ruth, service user]

Ruth's reply touches on three of the core themes identified within young people's discourse on the nature of relationships within mental health care: (1) communication; (2) equity and power; and (3) bonding and connecting. Underlying these themes are empathy, and human contact/care. A number of those interviewed, including carers and keyworkers, talked about the importance of about '*building relationships'*. This metaphor encapsulates the essence of what lies within the other themes, central to it is *'time'* and *'consistency.'* It is also a useful metaphor to appreciate how young people might experience the move from CAMHS to AMHS. For some this represents the collapse of a familiar structure and its contents, while for others it is the opportunity to rebuild and occupy a different space.

### *5.5.2 Communication*

Communication is central to what young people identified as important in their relations with mental health services. The opportunity to talk, to be listened to, and to be heard or understood, was repeatedly mentioned by young service users as the basic requirements of their relationships with keyworkers or psychiatrists, and other staff. When these components were present the relationship, and the therapy/intervention, was invariably rated positively. Fiona described the experience of being able to *'talk'* to her keyworker about *'the stuff that's going on, trauma and stuff like that'* as *'freeing'*

> *it was so freeing just to let go of all that, just to talk to someone about it, and she just made it amazing. She's just so real and so... probably the best person I've ever met in my life. [*Fiona, service user]

Being able to *talk to* clinicians was almost synonymous with having a good relationship with them. A number of young people clearly valued the opportunity to have a *'conversation'* with their keyworker, where the talk was not all one way, and they could *chat* informally about shared interests or aspects of each other's lives, that were not necessarily directly, or obviously, related to the problem the young person presented with:

> *I adored them both because, like I said, I would generally speak to them as if I was just having a chat to a friend. I would ask &CAMHS KW 1 about her move to &another city, I'd talk to &CAMHS KW 2 about her dog and stuff, a bit of chit chat, and that makes it easier for me to open up.* [Gabrielle, service user]

Others also valued the opportunity given by CAMHS keyworkers to discuss day-to-day events and issues.

> *I was glad to even take time out to just have a chat, not even to talk about what was eating disorder related, just talking about how I had been, what I was going to do and my plans for the rest of the week. It was like that, it was nice.* [Jennifer, service user]

Service users commonly described how being able to *'talk to'* practitioners as essential to the relationship, linking this ability with *'trust.'* When we met Bradley prior to his transition to adult services one of his main concerns was that he would not *'find anyone else like [his CAMHS keyworker] to talk to, I just feel I can trust her.'* Meeting up again after he had a few appointments with his new keyworker in adult services he again referred to *'trust and honesty'* as the most important ingredients in the patient/practitioner relationship. As a young transgender man he was waiting for hormone treatment and an indication of when he could expect to have surgery. Information and *honesty* were of crucial importance to him.

However, various young people cited instances, from both CAMHS and AMHS, when they felt *'intimidated', 'patronised', 'invalidated', 'judged,'* where they were made to feel *'silly'*, or feel they were '*not taken seriously.'* The effective use of questions was identified by a number young people as key to communication, to relationships, and indeed to engagement:

> *The more you talk I suppose the more...it's in the way they act as well. If somebody was really off with you and they'd be like (...) They wouldn't really ask questions about you, they would just be asking questions about what they think is right or what they think, you're not going to be like looking to talk to them every week or whatever it is. But if you have somebody that's asking about you and about what's happened and about your past week and not just your actual past, it's easier just to build on that.* [Christine, service user]

While some commented on the use of sensitive and intuitive questions and how they helped them to understand and process their problems, others took issue with the nature and style of questioning. In a way that implies aggression against her, one young woman talked about two clinicians *'hitting [her] with all these questions'* on her first appointment. Another described how the questions she was asked were *'very forward'* and even though she was not comfortable answering all of them, '*they still pushed for you to give an answer."*

For example, a young gay man, who left CAMHS to attend a community and voluntary service found some of the questions he was asked in CAMHS both inappropriate and demeaning:

> *Like cause I came out as a gay male just before that, and they were asking me questions that I thought were very inappropriate about my sexuality. Like one of the men in there turned round and said, "If you were standing in the middle of town and a really good looking woman came walking along would you talk to her?" and I was like, that's got nothing to do with my mental health, it's none of your business like, and I just thought they look down on you a lot.* [Don, Action for Children]

Before he moved to adult services Eamon expressed a hope that his new keyworker in AMHS would understand him and take a genuine interest in him. One of the ways he expected to measure this was their ability to ask the *'right questions.'*

> *Like I've said before, I just hope that there is understanding. I just hope that they can take an interest and, it's not like I want them to take an interest in me, you know, maybe it's just... I like when someone is you know, there's a mutual interest in each other, especially in a conversation, you know. If you're sitting with somebody and they just don't want you to hold a conversation, they're not really interested, they're not asking the right questions - that would make me anxious. I'm like, am I wasting my time, or whatever. So I just hope that they're nice. [Eamon, SU]*

In the transition to adult services Sally recounted how she completed '*a mental health assessment'* form with her CAMHS keyworker. In doing so she said *'quite a lot of things I never mentioned to [keyworker] came up.'* When her keyworker asked why she had not talked about these *'things'* to her before then, Sally responded *'because you didn't ask me.'*

Other barriers to communication, all of which had a negative impact on relationships with practitioners and effective engagement with services were outlined.

Conspicuous note taking was regarded as communicating a lack of genuine interest and empathy to the young person. One young woman, who left CAMHS to attend a community and voluntary organisation, recounted how the two practitioners sat in front of her *'taking notes constantly'* while she was *'trying to explain'* how she was feeling. She went on to say:

> *and they're constantly writing down and saying how did this make you feel, even though you've already told them, and you keep repeating your story over and over again every time that you go. … You'd swear they were taking notes on what you were wearing as soon as you come in the door.* [Roz, service user]

Most perceived the interaction and atmosphere with clinicians as overly formal, communicated in part by the physical environment, how the practitioners dressed, their body language and positioning within the room. Young people reported feeling more at ease, relaxed and

comfortable when keyworkers met them on a more equal basis, when they were prepared to meet them in a café, at their home, or took them for a walk in the park or the grounds of the hospital. The importance of being *'real'* being authentic mattered to young people.

When we first met Steve he was looking forward to moving to adult services, believing it would suit him better and his *'full blown, adult mental illness.'* When we met again a few months after the move he compared the relationship with his CAMHS consultant to the one he had with the psychiatrist in adult services. Steve described his CAMHS consultant as a *'saviour'* as someone who *'went the extra mile,'* he felt that she knew him, knew his background, and was able to communicate this to him each time they met. He now feels that the pressure on adult services and psychiatrists means this connection, or type of relationship, is no longer available to him, or even possible:

> *It just feels detached. It doesn't feel like a personal healthcare service, in the sense that it doesn't feel like a one to one conversation with a person, like it is now - me and you talking about something. It's you, him and your record and… it's you and the record, pretty much, and he's just going through what your past is and stuff like that, or to build a picture of who you are and stuff like that. So it feels like a detached and dislocated kind of plan to do things ( ) But, you know, when I walk into the bigger offices and stuff like that it's "oh, he has depression" and this and that, it's not "so he has depression, I remember that." It's reading the book. "Well, according to this he has depression. According to this he's on that medication, according to that... he is, he is he is." It's dislocated; it's just paper.* [Steve, service user R2]

### *5.5.3 Bonding and connecting human contact*

Feeling *'detached'* and *'dislocated'* are far removed from feeling *'connected'* or *'bonded.'* The importance of feeling a connection with keyworkers or psychiatrists was named consistently as an important ingredient in the therapeutic relationship. Having a *'connection', 'clicking'* or *'bonding'* with practitioners was associated with a sense of *'safety', of 'comfort' and 'security,'* all of which facilitated good communication and engagement. Being able to share and express the self through *'humour' 'banter'* and *'sarcasm,'* to connect around shared interests and *'similar personalities'* were all part of what made the contact with practitioners, and ultimately with services work better.

In the context of the transition to adult services, the established bonds and connections with CAMHS are, necessarily, broken. Given how important this aspect of care and service is to young people it is understandable that some describe the move to adult services in such emotive terms. The sense of loss and ending they experience when leaving CAMHS can be accentuated by the very different culture of care they encounter within adult services. Indeed

keyworkers also recognised that breaking the *'link'* with CAMHS can be difficult for young people, and that the difficulty is compounded by the different approaches offered in CAMHS and AMHS.

> *I know with Karen, she was very worried about transferring over to adult services, because I think she had a good link here and I think she had a really good relationship with any of the professionals that she was involved with, ( ) I think sometimes we do work a bit like a family here. I don't know, maybe that's wrong to say that, but I think it's just a wee bit more clinical in adult*. [Barbara, Karen's Key worker]

### *5.5.4 Equity and power*

It is argued that working within a recovery model, the relationship between clinician and the service user requires a shift in therapeutic stance so that staff move from positions of *'authority'* to act more like *'personal trainers'* or *'coaches'*: *'offering their personal skills and knowledge, while learning from and valuing the patient who is an expert by experience'* (Roberts and Wolfson, 2004). Borg and Kristiansen (2004) include *'collaboration as equals'* and *'reciprocity'* among the key characteristics for a recovery orientated approach from practitioner level. These characteristics and three other key components (openness, a willingness to go the extra mile, and a focus on the individual's inner resources) were all named by the young people when talking about their relationship with practitioners. In over half of the individual interviews with service users, and all of the group interviews, the question of equity and status was raised as an issue in some form. And for some it was linked very directly to their notions of recovery. Within the context of this theme, young people (and some parents) commented, both positively and critically, on what practitioners communicated through their social and interpersonal skills, their attitude, body language and tone of voice, attire, use of language, and willingness to take their views and feelings on board.

A few young people reported being *'put off'* and feeling *'intimidated'* by practitioners who were *'all dressed in suits.'* In contrast the more relaxed approach within the community and voluntary organisation was associated with a more equitable relationship where the young person did not feel pressured to engage in work they were not comfortable with:

> *With CAMHS it was just full on, it was really uptight and I just found Action for Children was just really relaxed and far better. Like they weren't in big suits, they were wearing normal day clothes, and it was a really relaxed atmosphere, everybody was really nice and if you weren't comfortable doing something they didn't push you and force you on to do it.* [Roz, service user]

Fiona conceded that while practitioners have the authority in prescribing medication, she felt somewhat frustrated that her wishes or concerns with regard to her medication in Adult Services were not acknowledged or taken on board. She very much identifies the psychiatrist's attitude as authoritarian – an approach that does not sit well with her:

> *They didn't really listen to me. I said to him in my last appointment that I wanted my... Not wanted, I did want, but I didn't say it like that, that I would have liked my sleepers upped or changed to something a bit more effective to knock me out a bit more. And he was like "no, I'm not doing that." And I was like, "well, could you not just listen to me?" And he was like "no, we're not doing that." And I'm like "right, okay." Or about my anti-psychotic, I'm like "can I have it changed please, because it's not working?" And he was like "that's up to me." I'm like "Oh you patronizing little... man." (….) He's almost looking down on me, judging me a wee bit, and I don't like that. They never did that in CAMHS, they listened to me. Even the way he puts things. He tells me what to do, rather than go "We'd like you to do this." I'm not a big person on authority.* [Fiona, service user]

Young people were upset by the unwillingness of staff to permit shared decision-making and in the case of Belle, below, this contributed to her decision to disengage from statutory services. Belle was not attending school and while she acknowledged the legitimacy of what information needed to be shared between CAMHS and her school, she objected to the fact her keyworker turned up in the school meeting without her prior knowledge. She found it *embarrassing*, *awkward* and an invasion of what she regarded her business:

> *Because I was refusing to go to school, so like he decided he wanted to come into the school to the meeting, which I thought was really embarrassing, because people know he works for CAMHS like, and he just like walked into the meeting ( ) and I was like, oh no. I know the school has a right to know but it's really awkward like cause I would rather talk to the school more than I would talk to CAMHS, cause I felt a closer bond to the school. But he was just sitting and writing all the stuff down that had nothing even to do with CAMHS, just to do with school, and I was like, this is none of your business. So like that just made it worse, so I just refused to go, I was like no.* [Belle, service user]

By contrast, when young people talked positively about the relationship with their practitioners, the aspects that made it work well included being respected, a sense of mutuality in interests and personalities, trust, having their needs and views recognised and taken on board. The importance of a two way exchange, whereby young people gained a greater understanding of

their problems through an equitable interaction with practitioners was clearly valued, and identified specifically by a few young people as being central to recovery:

> *But I think recovery for me now means just getting my life back on track, as a whole, just getting sorted, getting everything done, being optimistic, doing what you've got to do; just leading a normal life.*
>
> *Interviewer: Right and what does "getting sorted" mean?*
>
> *Getting sorted means ( ) everything that I've talked about with people, you know CAMHS and adult services, all those things that they perceive as a problem. I just want on some level for me to understand them more, which is already happening, and on some level create a coping mechanism and eventually, hopefully, one day they'll be so miniscule that I won't even notice them. So I think that's what "getting sorted" means.* [Eamon, service user]

The following quote summarises the essence of how a more equitable patient practitioner relationship might work:

> *I don't know how else he could do it better. Just look at me like I'm the same as you, treat me the way that you'd like to be treated. If we were in opposite roles and I was sitting there and telling him "no, no, no", or the way that he talks down to me, he wouldn't be very happy about it, I know he wouldn't. He'd have said something to me about it. Just act differently, just treat people the way you'd like to be treated, I think. That's the way I'd do it if I was in his position. But, you know, he's the doctor and he can do what he wants.* [Fiona, service user]

### *5.5.5 The role of carers*

The social environment young people occupy, and the nature of relationships they have with family and carers, can play a key role both in their experience of mental health services, and their recovery journey. A systematic review of studies that looked at the role of family in recovery models for those with mental illness, found that family interactions may determine recovery (Reupert et al, 2015). As is recounted elsewhere in this report, the nature and degree of parental involvement in young people's engagement with services varied, and was facilitated to a greater or lesser extent across CAMHS and adult services. The degree to which parents regarded their role in their child's recovery was not specifically asked but it nevertheless arose in the course of the interviews.

Several young people referred to the support they received from their parents, particularly mothers, as being crucial to their care. Karen, described her mother's support as *'really important'* and something she *'couldn't do without.'* Interviewed before she moved to adult services, she anticipated that her mother would not be as involved once she left CAMHS. She described this change as akin to being *'let off a leash.'* Karen's father was also actively involved in supporting her, and as part of her planned disengagement from CAMHS he took her on a drive through her local town pointing out various voluntary organisations, telling her she could *'call them any time.'*

Other parents, similarly, did as much as they could to support to their child, in order to maximise their engagement or benefit from mental health services (taking them to appointments and attending appointments, participating in family therapy, monitoring medication, monitoring and endeavouring to reduce risk, visiting inpatient units) or to provide additional support alongside statutory provision, including private therapy. Parents valued the willingness of staff to provide continued support and advice. For example, one participant related how, if her daughter was *struggling*, she was able to join her appointment for the first five minutes to *'open the thing up.'*

> *I suppose as parents you can read your kids like a book [ ] I know when Ruth's bottling things up, which means I am then able to go down [ ] … I would say to Ruth 'is it ok if I go in for five minutes and the two of us will speak to AMHS keyworker together [ ] I only have to go in for a few minutes and just open things up, I can walk away and leave it.* [Beth, Carer]

Beth and Ruth were interviewed together, and Ruth agreed that her mum's intervention in this way was helpful. The discussion between mother and daughter touched on the impact Ruth's illness had on the whole family. As well as wanting Ruth *'to recover',* her mum acknowledged that the whole family had been affected by Ruth's illness, and also required their own kind of recovery.

Another service user who suffered from depression touched on a similar theme when she suggested that her mum's ability to cope was directly linked to her own level of coping. Gabrielle was very positive about her transition to adult services, not least the opportunity it gave to be prescribed a different, more effective, anti-depressant. Her keyworker in adult services arranged for her to attend a voluntary sector organisation where she joined *'recovery classes.'* Her mum continues to be very much involved in her daughter's recovery (and receives regular individual appointments with the adult team) and as Gabrielle puts it, *'she is pretty psyched at the minute, going into all my classes and stuff.'* Most parents mentioned

having to reduce their work hours, or even giving up work, to provide care and support for their children.

More generally, the move from CAMHS resulted in a reduction of parental involvement with mental health services and this was considered problematic for some. For example, Jennifer, who received a diagnosis of borderline personality disorder when she moved to adult services, felt it would have been beneficial for her parents to attend initial appointments. Instead, her father felt obliged to research the diagnosis on the internet, having been *'taken aback'* by the diagnosis. She tried to explain to him, with her own limited understanding, what it meant:

> *I have tried to explain to them when I don't know how I'm feeling, and I get really agitated or angry and try to explain that I don't know why I'm feeling like this. It's getting to the point where, I don't know, if I'm supposed to know and I don't know what's going on, because I don't know the diagnosis, properly. When I feel weird or something's come over me, I don't know is this supposed to be happening? Is it a part of borderline or is it something else? Am I ill? [Jennifer, service user]*

Not all adult teams employ such a strict policy with regard to parental involvement, and there is evidence that, with the young person's permission, some parents remain involved with services. Ruth's mum said she saw the adult team once a month on her own, and can join her daughters appointment for the first five minutes if necessary, to help raise an issue for her:

> *And the same has happened with adult services, which has been good. Adult services see me on my own once a month just to see how things are, to see…which is brilliant, it is really good, really helpful. [ ] I know when things aren't good and I know when Ruth's bottling things up, which means I am then able to go down and just ... I would say to Ruth: "Is it okay if I go in for five minutes and the two of us will speak to &AMHS KW together?" and Ruth will say, Yep, because she knows herself she's struggling, and I only have to go in for a few minutes and just open the thing up, I can walk away and leave it.* [Beth, Parent]

### *5.5.6 Other sources of support*

The effectiveness of any support or intervention provided by statutory services is likely to be mediated by the social context in which young people live, and the relationships they have within family, their neighbourhood and the various communities they move through. Young people's help seeking for mental health problems was not a particular focus in this study, but has been documented in research elsewhere (Rothi and Leavey 2006; Rogler and Cortes 1993). The IMPACT study was, however, interested in what other sources of support young people were in contact with or, were aware of, as they made the transition between services.

In summary, half of the eighteen young people interviewed as part of the core study described the wide-ranging support they received from community and voluntary groups, in addition to the statutory services (see Appendix 8 for list) while the rest were unaware of any community organisation that might be helpful to them. Social media was mentioned as an important source of information and support in relation to their mental health, namely Youtube, Instagram, Tumbler, and Google searches. Three young people had support from school counselling or home education, and one young man mentioned having social work support (interviews with related keyworkers and parents suggested that social services were involved in one further case). Interestingly, friends were seldom mentioned in this context. Where friends are discussed as being helpful we noted that that these friends also had mental health problems The aspects of support that young people valued from the community and voluntary sector included the role they played in relation to the statutory services, mostly in terms of assisting help seeking, advocacy or confidence-building through counselling and general encouragement.

Parents, mostly, were positive regarding the community sector support for their children. Richard's mum talked positively about the social aspect of the support he received from a mentor from REACT[10], and Suzanne told how her daughter *'flourished'* when she was allocated a place on a Start 360[11] course. Family and social networks are recognised as important components in the recovery process for people with mental illness (Rogler and Cortes 1993) the additional support they, and community organisations provide was largely recognised as positive by those interviewed for this study. The elements that mattered within these other sources of support, as highlighted by those interviewed, were primarily advocacy, mentoring, and social support.

The interaction between statutory and community services will be considered more fully in Section 5.8, below, on structural processes, where the challenges and the barriers, as well as the successes and facilitators to inter agency working will be considered from the perspective of both sectors.

## 5.6 Stage 3 Findings Part 3: The impact of structural processes on transition

How young people and their carers experience the transition between services is affected by the organisational practices in operation, and the relationship between practitioners across CAMHS and AMHS. The experience is additionally affected by the interaction with other agencies and services involved in the young person's life at the time of transition. In this

[10] React is a community organisation supporting marginalized groups and individuals through a range of projects
[11] Start360 provides a range of services and interventions in the areas of health, justice and employability.

section we have drawn specifically on data from interviews with professionals in CAMHS and AMHS, (including nurses, psychiatrists, social workers and managers) and with practitioners and managers within the community and voluntary sector (youth workers, social workers, counsellors).

The nature of working relationships, the channels of contact and communication, and the exchange of information and knowledge between practitioners, within and between services, emerged as the dominant themes concerning the transition process and the transfer of care between services. Data collected from across all five Trusts suggest, that while protocols and policies exist to facilitate and direct the transition process, the outworking of these is seldom linear. There is room for individual interpretation of what will work best for the young person, or is possible given circumstances and available resources. The experience of transition can also be affected by the difference in care philosophies between the services.

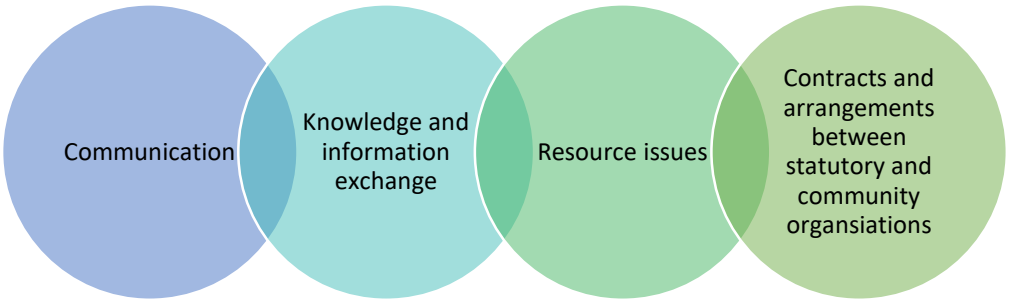



**Figure 5.3** Part 3 Analysis: Impact of structural processes

Four broad themes emerged from analysis of the data in relation to the organisational practices across and between services around transition:

- Communication
- Knowledge and information exchange
- Resource issues
- Formal contracts and arrangements between statutory and community organisations

Unpacking each of these themes provided a clearer insight into the multitude of factors that influence the experience of transition for young people, and those involved in their care, directly or indirectly. The issues that impede smooth transition and the factors that promote good practice and experience are highlighted.

### *5.6.1 Communication*

Communication is an obvious requirement for the effective transition of care between services, and agencies. How it happens and what is communicated is perhaps not always as consistent or as fulsome as some of those involved in the process would like. Those interviewed indicate

that interagency communication (formal and informal) may differ substantially between Trusts. Differences in practice and culture still evident within Trusts is perhaps a legacy of structures and relationships that existed before the Health and Social Care Reform in 2007 when the number of Trusts in Northern Ireland was reduced from nineteen to six (including the Ambulance Trust).

Academic meetings, head of service meetings, team lead meetings, multidisciplinary meetings and the Continuing Professional Development programme at the Royal College of Psychiatry offer opportunity for communication and shared learning at varying levels across all trusts. Personal relationships built up between staff over the years facilitate a more informal line of communication, which is also used to enable young people to move from CAMHS to AMHS. While this more informal relationship between practitioners was regarded as positive in terms of transitioning young people between services, it was also recognised as limited. For example, this form of communication and information-sharing is not necessarily open to new members of staff, and only lasts as long as both parties remain in post.

Other forums for interagency contact, particularly between the community and voluntary and statutory services, included family hubs, recently formed Health and Wellbeing hubs, and social service case conference meetings. Formal service contracts between the statutory and third sector organisations facilitate varying levels of contact and collaboration between the sectors. Very few participants had experience of working in both CAMHS and AMHS. Those who had work experience across the different sectors highlighted the benefit of this experience as it facilitated mutual knowledge and respect and added another layer of informal contact and informal transition practice.

The telephone conversation was valued as a quick and time efficient way of getting or giving information, and within some Trusts was a first point of contact between clinicians to discuss possible referrals. (As we see later the success of a telephone call was sometimes dependent on the existence of an already established relationship or connection between practitioners). In addition, the Trusts have set up more structured forums to facilitate the discussions and decisions around young people's transition from CAMHS.

### Multidisciplinary meetings and transition protocols

#### *Transition Protocols*

All five Trusts have written Transition Protocols (see Chapter 3) which provide instruction on the transition process and the transfer of care between services. The protocols define the delivery of information (what, when and how) to be communicated between services. Each Trust has their own individual protocol (Belfast and the South East Sector is combined), and their own structures to facilitate the transition process. The Belfast and the Western Trust,

hold Transition Panels. In the Northern, South Eastern and SHSCTs transfer meetings and multidisciplinary meetings are held as part of the process.

The findings from a content analysis of the protocols have been presented in Chapter 3 (Service Mapping). Further feedback on their practical application from those who use them is presented below.

Practitioners in both CAMHS and AMHS were generally aware of the existence of a Transition Protocol and in some instances both services were directly involved in its development.

> *Yes, we have a protocol to manage that handover and transition. It was developed between ourselves and CAMHS colleagues; so we worked that up together just in terms of getting something that makes it fit and helps manage that transition quite smoothly*. [CMHT, AMHS]

Others admitted an awareness of a transition protocol but not necessarily having access to it, or being certain that they followed it in their practice. Some clinicians suggested that it was not always necessary (or possible) to follow it to the letter. Some clinicians were unaware of the detail of the transition protocol within their Trust. One psychiatrist was unaware of its existence and told how she depended more on the *'old-fashioned consultant to consultant referral:'*

> *The very fact that I don't know of one (Transition Protocol) suggests that there isn't one, and if there is, it's probably old and dusty and we don't adhere to it. But it may be that the assessment centre adhere to it very closely, and my experience is that the consultant would be ringing and you just go ahead from there, an old-fashioned consultant to consultant referral that takes place and then the new route in to the assessment centre.* [AMHS Psychiatrist]

However, more commonly, most clinicians accepted that the introduction of the transition protocols improved the exchange of information from CAMHS to AMHS. The situation prior to the protocol was described in a focus group with AMHS practitioners as *'a bit ad hoc'* and depended on the *'relationships between teams in particular areas.'*

> *But since the protocol it is definitely smoother and then within the protocol there is a summary that the CAMHS team would give to adult mental health and that's very much outlining therapeutic input, diagnosis, any psychological input, you're very clear about what that person is coming with, what they've already been tried with or given treatment for, so then we can move forward. Before that I suppose there would have been difficulties.* [Community Mental Health Team Lead]

A group of psychiatrists (primarily from adult services from a single Trust) felt that the transition process had improved since the protocol was drawn up, but remained concerned about information-transfer from CAMHS to AMHS, in particular how late transfer of notes delayed clinical consultation with the young person. One psychiatrist said he sometimes received a full photocopy set of CAMHS notes, while in other cases he *'might get the last contact letter from the social worker or keyworker which doesn't tell you the same story at all.'* Another adult psychiatrist agreed that having to wait and chase up notes with *'phone calls and lots of letters'* for *'many, many months'* affected the nature of the work that could be done with the young person:

> *I've found myself on several occasions seeing patients with that sense of just doing nothing with them because I can't really make any clinical decisions until I've seen what medication they've been on the past or have some sense of what type of treatment they've had and you might have a slight summary of that but you don't have the detail that you would like to have* [AMHS Psychiatrist]

We found some disagreement about the optimum timing on the transfer of notes with one position indicating the need for *patient consent* for the transfer of notes obtained well in advance of the point of transfer while another stressing that the Trust transition policy states that notes should only be exchanged at the point of transfer. However, this may be problematic in the cases where CAMHS continue to engage with the young person. Access to patient records and the transfer of information between services was highlighted as an issue for AMHS practitioners in particular. A Nurse Practitioner in a Primary Care Liaison Team argued for a *'free transfer'* of patient information between services, and highlighted the problems associated with the use of different electronic databases across services. He advocated moving towards a system where patient notes could be accessed electronically across services.

> *Use cancer as an example, you fully expect that all notes go with you as you move, not just a summary [ ] we should be moving towards a scenario where AMHS can access CAMHS notes.* [Nurse Practitioner, AMHS]

Another practitioner with experience in both CAMHS and AMHS was familiar with, and listed the problems from both sides, namely; the fact that notes are not automatically closed in CAMHS when the patient is seen for the first time in adult services, the incompatibility of electronic data systems, and consent to share notes.

> *I suppose the other big difficulty is the sharing of information, because we work off the [Name] system, Adult Mental Health Services use the [Name Database], so if you've*

> *a young person in crisis and they're seen by the Adult crisis team they don't have access to their notes. [ ] I know that Adult Mental Health Services are getting the [Same System as CAMHS], but how much information is allowed to be shared? There's a whole thing around that, from a practicality point of view.* [CAMHS Practitioner]

In another Trust, an AMHS psychiatrist was satisfied with the more formal presentation of information which was now part of the transition process as he experienced it, *'the nice forms, risk assessment, points of contact, medical information.'* Prior to the transition panel and protocol he said *'information wasn't formalised*' [AMHS psychiatrist]

While the transition protocols either recommend (as appropriate) joint appointments with the young person and their keyworkers, this was not commonly adhered to. Clinicians, conscious of time and resources, advocated a tiered approach, tailored to individual and circumstantial needs. For example, one CAMHS consultant suggested that a *'straightforward'* case, or *'ADHD cases*' do not always require this level of input during transition:

> *There's some very complicated cases which obviously should have the gold standard of handover, you know you meet in advance with the adult team and then we would attend their first appointment and try to do the introduction and break the ice and so, on but as I say with ADHD cases, and things much more straightforward, I'm not convinced it's a good use of Trust time, [ ], but If someone has been attending CAMHS for half hour check on ADHD medicines and they're not maybe well known by whoever is looking after them at that point and the case is extremely straightforward, it's quite hard to justify two or three hours -by the time you do a meeting, by the time you drive down to [named other town] to introduce them when you know very little about them. And I wonder if our policy should perhaps reflect that a tiered approach to it might be better, from a Trust point of view.* [CAMHS Consultant]

In summary, the level of contact and the exchange of information between services vary across and within Trusts. It is dependent on the nature and history of relationships between practitioners and teams, the formal structures in place to facilitate transition discussions, and the resources available to follow guidelines and protocols. There was a certain level of frustration that despite (or perhaps because of) these factors the optimal transition for the young person may not be realised.

### *Transition panels*

The Belfast Trust Transition Panel is scheduled to meet every month, the Western Trust every quarter. The panels formalised the contact between CAMHS and AMHS staff around transition cases, while also creating the opportunity for greater contact and the development of

relationships between practitioners. A psychiatrist from adult services said that face to face meetings with CAMHS staff at the panel '*improves relations a lot'* and has formalised both the referral process and the actual relationships between services and staff. Another clinician made a similar comment, reflecting that the panel takes away the risk associated with a dependence on good relations between clinicians and suggested that it *'made a huge difference to managing referral on both sides*:'

> *Good relationships are okay provided they're there, but if they're not there then it's difficult. You're sort of depending on people being able to talk to one and other, and it shouldn't be like that. When you're around a table here, for one, it exerts more authority, I think. If people are debating about where somebody should go then obviously it gives a firmer voice to it, but also it stops that...you don't want to be tramping somebody around a whole load of services just to get them to go where they're supposed to be going*. [CAMHS Keyworker]

Prior to its setting up, a Psychiatrist believed CAMHS staff found it difficult to access and navigate the *'labyrinth'* of adult psychiatry. Referrals would *'pop up in odd places'* and take time to filter down to the correct team. The panel, he believes, was successful in making the referral process more efficient. The following interview extract highlights the level of suspicion and frustration experienced within CAMHS and the impact on their policy and practice with the advent of transition systems.

> *Because we then started looking at some of the referrals of people looking to transition and we were going, well actually does this need Adult? So we had a lot of learning to do as well as to what we wished to happen and for what reasons, [ ] But it also gave us a great opportunity to look beyond what adult mental health offered and to look at what is offered within the voluntary sector as well, [ ] One of the big gaps in the adult service was to looking at, you know, those families who may be needed on-going family therapy or different pieces of work that we didn't offer at that time. There's been big changes in Adult, they now do offer that. But I think that interface was difficult. For me, when we started having the transition meetings there was kind of a belief in CAMHS "well, what's the point?" Some clinicians' belief would have been "well, what's the point in referring onto adults, they'll not see them anyway. Refer them back to the GP and the GP can access it, if need be." So that actually was the transition for a lot of those kids, or unless, like [NAME] says, you had a kid and you had a significant relationship on a particular team and you knew you could ring that person up and you could follow up, and that definitely did happen quite a bit. But I think, from our CAMHS perspective, our expectations of what that child and family needed was a wee bit idealistic*

> *sometimes and maybe we'd lost the recovery model a bit and our thinking about developing resilience with it and developing these young people and families so that they could function at maybe at a lesser level of support than we would have expected. So I think we had learning as well to do.* [CAMHS Practitioner]

The success and efficacy of the Transition panel as a structure was discussed at the IMPACT Workshop Consultation. A Clinical Nurse Specialist from CAMHS and a Service Manager from AMHS acknowledged in one of the break out groups that while the Transition Panel represented good practice it *'was not enough.'* At the same event, but in a different group, other opinions were expressed. A Consultant Psychiatrist was not convinced that a formal Transition Panel was always necessary to discuss possible referrals to adult services. Working across a large geographical area this psychiatrist suggested that *'a good phone call'* or attending the AMHS psychiatrist's team meeting, when deemed necessary, was a more efficient use of time:

> *…or some version of the panel there always has to be flexibility, in some cases a good phone call would be completely adequate, time is always an issue, there has to be some flexibility around the panel I think*. [CAMHS Psychiatrist]

Similarly CMHT leads in another Trust did not think the structure of a transition panel would necessarily improve the process. With nine community mental health teams they felt that transition decisions were best made at a local level due to *'differences in each team in each area.'* The logistics of arranging a full panel meeting are evidently difficult for clinicians under a lot of time pressure and working across large geographical areas. Those who worked in the same building or same site as their service counterparts associated this with better working relationships and greater knowledge and understanding of the other services. The team lead for a Primary Care Liaison team said working in physical proximity was helpful in this regard:

> *The best thing is to talk face to face (CAMHS and AMHS or different teams ) If you're based in the same building the closer the relationship, there is more understanding of what the other teams do.* [Primary Care liaison team leader]

Similarly a social worker who worked within an Adult Service Addiction Team and then latterly in CAMHS found his knowledge of both services useful when it came to making a referral to adult services and the addiction team. The fact that both teams were based in the same building also helped:

> *When I think back on a few, when you reflect on it, we've the luxury that we're very closely linked with CAMHS geographically, [ ] and even other mental health teams are not far away. So you would have had the formal meetings, the transition meetings,*

> *where they would have identified the young person, but we had the informal discussions about young people as well. You didn't have to wait until the meeting; even six months prior somebody would have even spoken to you. What you would have had is people consulting with us [in AMHS] around a young person they were working with who had a drug and alcohol problem.[ ] and then when it came to that transition you knew that a lot of the assessment work had been done, particularly around the drugs and alcohol pieces. When it came to the transition meetings you were nearly aware of who they were talking about and the issues. [Social Worker, CAMHS & AMHS]*

A team manager from Adult services found it useful to meet with CAMHS keyworkers to *'get a feel for what the young person might need.'* Such meetings were easier to organise as both teams were within walking distance. It is notable, by her own admission, that such meetings do not include the young person, and given their timing do not include the member of staff who will eventually be their AMHS keyworker. This practitioner acknowledges that both would enhance the transition process but would require additional resources:

> *The CAMHS community services were located very close to our team – they were a walk away, so we were able to organize for a Key Worker to come and have a chat about the young person and get a feel for what they might need. But that could be taken further if we had the resources to meet with the Key Worker who was allocated for them in Adult Services.* [AMHS Practitioner]

Working in close proximity is impossible for some teams, particularly those spread across large geographical areas. Technology was mentioned as helpful in these circumstances. The Western Trust use video conferencing to connect the two sectors for Transition Panel, and a CAMHS consultant in the Northern Trust highlighted the benefit of video link to discuss transition cases with adult colleagues:

> *From a CAMHS point of view my experience has been extremely positive and they seem to happen at good speed and work very well, and the video link and the software in the Trust and Adult accommodate us using that it saves travel time.* [Consultant Psychiatrist, CAMHS]

Most of the young people interviewed were aware of discussions held in relation to their transition and transfer, and some observed that meetings, such as those described above, did not necessarily make them feel included in decisions made about them:

> *I felt that it was more done without you and it was about you. Like if Adult Services and CAMHS were talking, if you weren't there, I wasn't part of it, I was just being told about*

> *what was happening at the meetings, and I was like, this isn't really giving me a good feel.* [Ruth, service user]

While acknowledging that the inclusion of service users and carers in such discussions was inadequate, or was not practically possible, clinicians did think that the situation had improved in recent years. A Nurse Practitioner in CAMHS observed improvements in this regard in Beechcroft:

> *Certainly from an inpatient perspective I've noticed an improvement within Beechcroft where the transition period, the discharge planning review meetings that are held, that the staff would be invited into it then, so that the young person and family could actually meet the new professionals.* [CAMHS Practitioner]

And one practitioner in AMHS drew attention to how the adoption of a recovery model within the service meant that *'the service user is much more involved in every aspect and every decision that's made.'*

The introduction of Protocols across the five Trusts has evidently introduced structure and procedures that enhance the transition process. Transition panels and meetings, as agreed by protocol, happen in various formats across Trusts. The Protocols are generally applied flexibly, dictated by the individual needs of the young person, the requirements of the teams and their structure, and local resources. The outcome for the young person is dependent on these and many other factors, mostly resource dependent. Acknowledging the differences in mental health provision across the region, this practitioner did not think that a standardised protocol or policy in relation to the transition process would be possible:

> *I think you couldn't have a protocol that's regional, like Northern Ireland, because each town is different and each town has different…not every town has a Praxis, not every town has a [Name of local Community Groups]. [ ] I suppose Mental Health Services, Adult Mental Health Services are different from Trust to Trust. [ ] That's my understanding of it anyway.* [CAMHS Practitioner]

### *5.6.2 Knowledge of services and sharing information*

A recurring theme expressed by practitioners was the importance of full and accurate knowledge of the service provided by the 'other'. As is outlined in the section on perceptions of mental health services, a shortfall in information can give way to conjecture and misperception in terms of service users understanding of services. Clinicians from both child and adolescent and adult services also expressed views in relation to the exchange or sharing of information between services. They welcomed it when it happened and identified areas where it could be improved.

Some CAMHS keyworkers questioned why they never had follow up conversations with their adult counterparts about the transferred service users. Given the extensive knowledge of, and contact they had with young people over the years they regarded this as a missed opportunity. A Clinical Nurse Specialist in CAMHS acknowledged the benefit of the discussions within the Transition Panel but thought further inter-service contact and conversations between keyworkers would be an advantage:

> *I think it's great, we [ ] discuss [the case] at the transition meeting and then they get allocated a keyworker within adult mental health. [ ] that keyworker does not always link in with us, even by telephone and things like that. Even though it's been discussed at the transition meeting, there might be a whole wealth of knowledge that we might be able to give them over and above that that could help them then. I know I have passed people on but I've never really then had a conversation with ...you get a letter to say that they've been offered an appointment and they're going to be offered a service, but it might be useful if....[ ] if there was a telephone conversation between the two professionals. I don't know where that stands with regards confidentiality and stuff like that there, I don't know, but it would just be an idea, something that might be useful.* [CNS CAMHS]

A clinical psychologist in a different trust echoed these same sentiments:

> *I don't know of anybody that has come back into CAMHS to say, 'can I just get a little bit more information.' You would have thought with the numbers that get referred on, over the years, there must be somebody somewhere thinking 'what was it that they did all those years?' What would have been useful in that situation? [Clinical Psychologist, CAMHS]*

In a focus group interview with CAMHS practitioners, the issue of continued communication between adult and child and adolescent mental health services was raised in relation to service user engagement. The CAMHS staff suggested that keeping the referrer in the loop and copying them into early correspondence with the young person *'can increase the chance of a young person engaging with AMHS.'* Equipped with such information they are in a position to follow up with the young person and encourage them to attend their AMHS appointments. The CAMHS staff highlighted the fact that this practice is not always followed.

A CAMHS consultant psychiatrist in a different Trust, like others, expressed appreciation of getting such information from her adult colleagues. Copied into letters to GPs she received feedback on whether or not a young person engaged with adult services or not, and was kept informed if an intervention was completed and the patient was discharged. She did not expect

to receive feedback on patients whom she anticipated being with adult services on the long term. CAMHS practitioners value feedback from AMHS but it is perhaps not consistent across the board.

Many CAMHS practitioners felt that the knowledge gap between the two services was a serious problem for staff and service users. Some clinicians felt that the more information on the nature of the work the young person did in CAMHS, what worked for them and what did not work etc., should travel with them to adult services. A booklet with *'the key facts'* to say '*this has all been done before and a summary of what was useful'* was suggested as a possibility by one clinician, as something that would greatly improve continuity of care and lessen anxiety for young people. Workers in the community sector echoed this need for practitioners to have more and accurate information on the other services:

> *Sometimes I think it would alleviate (the anxiety) if the young person knew, you know, you're going to meet such and such and this is a male or female doctor and you're going to see them at whatever building, [ ], a wee bit of, I suppose, a heads up on what an appointment with them is going to look like and how long it may take and a better understanding of what way adult services works in comparison to CAMHS.* [Youth Worker]

An AMHS consultant psychiatrist voiced frustration with one CAMHS team which he described as the *'weak link'* in the transition of one young person to his team. Their expectations of what AMHS could offer the young person in terms of family work was, according to him, unrealistic, and was based on their own lack of knowledge of adult services. This in turn created problems for the young person's initial experience of AMHS. A lack of clear information about 'the other' services is a significant handicap for practitioners preparing young people for transition out of CAMHS. It can build false expectations of services or, as we have seen elsewhere, create a vacuum which young fill with information and hearsay from a range of sources.

Additionally, clinicians recommended increased joint learning for all practitioners related to transition:

> *I think joint learning is crucial. It's not just the psychiatrists, probably the whole mental health team, the nursing staff and nursing staff in inpatient wards and all of that need to be more mindful of all those issues.* [Consultant Psychiatrist, CAMHS]

This was echoed in the Workshop Consultation. Participants suggested that communication between services was 'poor' that *'a lot of work [needs to be] done on preparation for endings'* and that this area and aspects related to transition and the transfer of services requires joint training.

One specific topic raised for a joint learning programme related to patients with a diagnosed personality disorder and the different understandings between CAMHS and AMHS in relation to this diagnosis:

> *And I think the other difference there's a certain group who – you know the personality disorder group, or the emerging personality disorder, we probably see that group more in terms of attachment, developmental trauma type base. When they move into adult, it becomes very much personality disorder, with more of an emphasis on them taking responsibility. So that's an area of difference. [ ] There needs to be maybe more joint, joint learning around that sort of thing.* [Consultant Psychiatrist, CAMHS]

The implication of such different approaches for young people making the transition between services is discussed below.

### *5.6.3 Resources*

> *It's an ever-changing world, because you develop relationships and things change so quickly, so fluidly. We don't get a chance to stabilize, to implement, to consolidate. You go back the next week and 'that's changed now, Johnny's not there or Paul's not there or Susan's moved on, or that service doesn't do it anymore'. [AMHS Nurse Practitioner]*

Resources generally determine many of the communication and organisational problems that we identified. Practitioners from both CAMHS and AMHS admitted that the pressure on services they currently experience, often drives the quality of service provision. Joint appointments, for example, are not always possible; parallel care is unlikely; and follow up communication between services is limited.

The pressure on resources also influences the nature of relationships and contact between services. In one of the multidisciplinary focus groups, clinicians admitted that the interface between services can be *'problematic'* with each side protecting their own resources and systems. They concluded that *'trust'* is a *'big issue'* and is sometimes lacking at services interface. Protecting resources and services and 'patrolling boundaries' was deemed unhelpful by practitioners in another multidisciplinary group, when the discussion moved to the needs of young people over 18 with ADHD. The fact that neither resources nor training were in place within AMHS to cater for this group was acknowledged as problematic, but the need to provide a service for these young people meant that boundaries needed to be dismantled in some way:

> *This thing of, 'you get your little boundary and you patrol it', that's not useful.*

In addition to a general sense of services being 'under pressure', a number of specific resource issues were identified as affecting the transition of young people between CAMHS and AMHS. The most common of these were:

- Family therapy provision in AMHS
- Provision for young people with ADHD and ASD
- Personality disorder
- The effect of resource shortages on care of young people
- The physical environment
- Formal contracts and arrangements between the statutory and community services
- Staff shortages, including specific shortages in clinical psychology and psychotherapy

Other issues raised included the mental health assessment provision in Emergency Departments for young people presenting in crisis; and funding uncertainty within the voluntary sector.

### Family Therapy

It was generally accepted by most agencies that CAMHS provided a holistic, systemic service that included support and interventions for young people *and* their families. Adult services were perceived as more singularly focussed on the individual, with less provision for families. One Consultant Psychiatrist in CAMHS, argued this was a deficiency in adult service and should be addressed:

> *I am amazed that adult psychiatry have no family therapy, or very little family therapy on their services, because there are lots of parents who have mental health problems and have children and then even young adults who are living at home. That work, family systemic work, I think there does need to be more conversations around the whole- about what confidentiality means in adult services and the carers who are looking after the people, perhaps sometimes people hide behind confidentiality.* [Consultant Psychiatrist, CAMHS]

Interviews with young people and CAMHS staff suggested that transition to adult services was sometimes delayed so that family therapy could be completed in CAMHS. A Social Worker in CAMHS, delayed the referral for one of her patients for this reason, believing that Adult Services did not provide the family therapy needed in this case:

> *…she's turning 18 this week, or next week, but I have probably delayed making her referral because she's in receipt of family therapy and there isn't access of family....I suppose that's another thing about adult services, they don't seem to have access to*

> *family therapy and yet it is quite a significant factor in their lives; family relationships and communication is often one of the major issues. I suppose, for Clara, the family therapy has just got up and running in the last month, or month and a half, and there's still a need for it, so rather than that being curtailed because she's having to be transferred, I have delayed the actual making of the referral, and hopefully that piece of work would be finished by the time then that she is going to the adult services. But it would actually be good to actually have a family therapist in adult services for a lot of those young people who are still living at home or where family relationships and family dynamics are a major factor in their ( ) symptoms.* [Social Worker, CAMHS]

That adult services did not provide family therapy or family trauma support was linked to the frequently made observation on the differences between CAMHS and AMHS, in terms of the systemic versus individual approach to therapy. A Service Manager in CAMHS was one of many who reiterated this difference, but also recognised the historical reasons for it, and the fact that such a hard line distinction was probably not completely accurate any more:

> *Maybe we think about things differently, thinking systemically about things has been CAMHS over the years, and historically we have handled things very differently. So I don't think it's a case of one caring more than the other, I think that just over the years we've built up different knowledge and experiences. Adult are making positive changes*. [Service Manager, CAMHS]

Family therapy in AMHS, however, remains a gap in service as far as practitioners from Child and adolescent services are concerned.

### Provision for young people with ADHD and ASD

The gap in services for young people with developmental disorders, including Attention Deficit Hyperactivity Disorder (ADHD) and Autism Spectrum Disorders (ASD) is a major concern raised across all Trusts. Service provision for young people with these conditions is varied across Trusts, as is their care pathways when they reach eighteen. Interviews with practitioners across the Trusts suggest it is a service issue under review or certainly in flux, and as such can present with complications for service users, and providers.

A nurse in CAMHS, described how one of her patients, aged 19, remains under the care of CAMHS as no service currently exists within adult service for young people with ADHD. A Nurse Prescriber in CAMHS takes responsibility for the medication of this young woman and of many others in the same position and these young people often need additional support as well as medication. When they present in crisis to hospital Emergency Department, responsibility between CAMHS and AMHS is confused:

> *I would have a few who would be still on my caseload who would be post 18, but there's no real place for them at the minute. It's not that there's no place for them, they're working on getting a facility set up in terms of ADHD, but what that's going to look like, I'm not sure. [ ] But what you would normally find is they end up showing up in crisis situations as a primary liaison or in adult mental health. I know I certainly have had one young person...Karen also has presented there as well, and has been seen in crisis. [ ] It was crisis intervention. She was admitted into hospital so they [adult mental health] did short term crisis work [ ] with her to get her over that crisis, and then it would normally be discharged back to the GP. Now they did get in contact with us, obviously, because she is open to us, but it can get, Karen is the only one of mine that is ADHD, but it's a lot more complicated, rather than the straight switch over with youngsters that don't have ADHD. There is a bit of a question, "well she is open to you, why are you referring to adult whenever you are seeing her?", and we're saying that we are only looking after the medication because she is...that's what our role is. It's complicated, because I know her GP has started her on anti-depressant medication as well and the GP is looking after that, and she is still involved with voluntary agencies.* [CNS, CAMHS]

The team manager in the same Trust identified the lack of provision in adult services as the reason why CAMHS have to hold on to some young people past transition age, and possibly into their early twenties. This, as was pointed out by a CAMHS Nurse and others, *'has an obvious consequence on the overall capacity of services.'* While medication management may be regarded as the main reason for transferring young people diagnosed with ADHD, their needs are often more complex:

> *(The Nurse Prescriber) [ ] sees the ones that are ADHD and are on medication, but I know that even though they're on medication and, say, that they're coming in for medication review and they're 19, it's not always straightforward. There are always other difficulties as well, which Julie would work with them in relation to. So it's not "ah we can't do anything like that", or "we can't listen to that". There would be another volume of work for the likes of Julie and things like that there, over and above the medication monitoring, even if they are 19, whatever it is they are.* [CNS CAMHS]

A group of community mental health team leads in a different Trust made reference to a *'huge glut'* of young people moving from CAMHS to adult services for ASD and ADHD medication management a few years earlier. Over sixty young people came across at the one time. These practitioners said while adult services were in a position to offer medication management to these young adults, their care had remained within CAMHS. It can only be speculated as to

why this may have been the case; perhaps the points raised in the quote above might be a factor:

> *The service was there but the consultant in the CAMHS side had held on to some. I think that person was moving on, and then the realisation was that 'oh, these people are all twenty plus.' So there was quite a few came over. I think there was sixty plus at that stage. The majority of the people coming across, it's because the meds have to be prescribed by a psychiatrist, so it was really for medication management.* [CMHT Leads, AMHS]

The fact remains that the transition for young people with neurological/developmental disorders is not straightforward. A Nurse Practitioner suggested that ADHD nurses could be placed within adult services to support the young people beyond their medication needs. As she points out, the situation at present is confusing for practitioners let alone service users, and likely to provoke unnecessary anxiety among young people:

> *Barbara: If there was a service and I think where we could ... we do have the transition meetings, which I think are great and I think they are very, very helpful for both adult and for ourselves, for a linking up and a joined up process. However it's just the fact that there is no place then at that point in time. I'm sure that's not easy for the young people either. If they knew that this was one place that was for them, it would make the transition much easier for them as well, because I'm sure it is anxious provoking for them.*
>
> *Pauline: That's it, and as we're talking about it, it's confusing for us as professions. So you can imagine what it's like for the young people stuck in that circle.* [Nurse Practitioners, CAMHS]

An AMHS Consultant Psychiatrist in another Trust admitted that she and her team lack knowledge and competence in dealing with ADHD; young people transferring from CAMHS could only expect medication management from AMHS:

> *That's all we can provide around ADHD, is around medication. We don't have, necessarily, the skills within the team to do specialist other types of work. I don't even know what that would be because I don't know much about ADHD.* [Consultant Psychiatrist, AMHS]

The transition for young people with a diagnosis of ASD can be as confusing. A practitioner from a voluntary organisation supporting young people and adults with autism questioned the

level of support provided by the statutory services for young people after the age of eighteen, which is something, he said, families worried a lot about:

> *One of the main issues with transition is a lot of families we work with have concerns when the young person hits eighteen, they seem to disappear off the map. The Trust has been trying to improve on this, but there is concern as to how fluid the service is at this stage. How good is communication? How does transition actually happen?* [Keyworker, Voluntary organisation]

Within the statutory sector, clinicians also expressed concern about the nature of services provided for young people with ASD, and recognised the difficulties associated with transition for this group. In a multidisciplinary focus group in one Trust, psychiatrists discussed the role and interaction between the mental health services and Autism Intervention Services within the Trust. They highlighted what they termed a *'disconnect'* between both. Psychiatrists held that while medication could be managed within psychiatry, the on-going care and management of a patient's anxiety issues etc. should fall within these more specialist services. The fact that services were under resourced and under developed was at the heart of the problem:

> *Quite often we find we're doing stuff that we feel, if those services were better developed we wouldn't need to be doing it. (..) For example every kid with ASD has a level of anxiety because the world is such a confusing place for him or her. So we would see that as part of their ASD, and therefore ASD intervention services should be able to manage that but quite often they're referred to us for anxiety management, so there's a kind of disconnect.*
>
> *Interviewer: And do you think then that would be better managed within ASD services?*
>
> *I think so yes, obviously if there is medication required we could be involved. But taking it out, this kid with ASD presenting somewhere else to treat their anxiety doesn't really make sense. The anxiety is part of who they – part of the whole ASD way of being. [ ] And that whole thing of other parts of the service feeling that one part has all these resources when in fact they don't, it's about working together I guess.* [CAMHS Consultant Psychiatrist]

A strongly held view by clinicians across the Trusts relates to a general lack, and an unequal distribution of, specialist services across Northern Ireland, suggesting that with limited resources services are trying to address unmet needs but that ultimately this is an area that needs to be addressed through the commissioning process:

> *CAMHS may be partly equivalent in each area. Support and Recovery will not. When you get into the likes of Personality Disorder services, Autism, you'll see significant differences in each of the Trusts. We're going back and saying we're not actually commissioned to provide all of this and we're seeing it as an un-met need. Maybe with our reconfiguration with the commissioning processes there might be a bit more evidence-based commissioning. The way it works at the minute, they'll ask us: "What are you doing about this?" and the Trust likes to please so they'll say we're doing something, they like to say we're doing something but it has never been commissioned, it's never got much beyond an attempt to set up an assessment service. These people, even if they are assessed, they are fairly limited as to what they're going to be able to avail of.* [Consultant Psychiatrist, AMHS]

Other clinicians observed that the while they are now prepared to take on the care of young people with ADHD (something that came about as a result of the Transition Panel), they are doing so without the relevant training, resources or management support, but do it *'on good will'*:

> *I have no issue with it. I think it hasn't been acknowledged in management. Nobody has asked and you feel... I have no problem doing it at all but you're out on a limb a little bit if something goes wrong, because you haven't been trained.* [AMHS Primary Mental Health]

Aside from the young people with ADHD who make the transition from CAMHS, there is a whole other group who are looked after in paediatrics for whom the transition is apparently even less clear:

> *I think there is a gap with ADHD for those kids are not known to CAMHS and have just been known to paediatrics and have been kept on, because they don't have anywhere to transition to. [ ] There's hundreds of them, from what I gather.* [Transition Panel discussion, Belfast]

CAMHS Psychiatrists questioned the practice of sending young people with ADHD who were *'very stable'* to adult psychiatry. Unless there was a comorbid presentation they felt that the GP could possibly manage the care, and so avoid giving the individual a *'psychiatric label.'* Care pathways for young people leaving CAMHS with ASD and/or ADHD are possibly not as straightforward as they might or could be, largely due to the lack of clarity in what care is available, or should be available after 18, and where the responsibility for that care lies.

One consultant psychiatrist in CAMHS, described the transition of a young man with autism and comorbid mental health problems as more complex than most of the young people she

transfers to adult services. She queried whether his mental health problems could be described as *'severe and enduring mental illness,'* and thus fit into the more typical criteria for adult services. As autism is a lifelong condition she states this means he is eligible for secondary care in any case.

> *Ian is probably more complex than the typical young person that I would be transferring, because he's got autism as well and because I have to think about his vulnerabilities from that side of things as well as about his mental health.* [Jane, Consultant Psychiatrist, CAMHS]

The gap in services for young people with ADHD and ASD in both CAMHS and AMHS, and the problems associated with movement out of, or between services, was highlighted across all Trusts. The difficulties that arise around the age of transition for these young people was identified as an area of concern for all, including parents. Practitioners in the Workshop Consultation agreed that this was *'a group that needed a lot more attention,'* and that greater attention should be paid to them and the needs of parents and carers at the time of transition. There appears to be a need for more training in this area and for investment in specialist services across the region.

### Personality Disorder

Differences between CAMHS and AMHS in the diagnosis of specific problems can create potential difficulties for young people making the transition between services. The debate between the services in relation to a diagnosis of personality disorder is one such issue. Receiving such a diagnosis in the first instance at adult services can be a shock for young people, and difficult to reconcile with the information and interventions they received in CAMHS. A number of young people who received such a diagnosis when they moved to Adult services talked about the impact it had on them and their families:

> *When I entered Adults, the first time I saw him he was able to tell me I had borderline personality disorder. And I was totally taken aback by that. I just didn't understand that my whole way through CAMHS they weren't able to tell me that. But I didn't realise that up to 18 they don't diagnose you with borderline personality disorder, because it's not really a thing over here, it's just like an act, but over in the UK it's like an order or something, or else it's the other way around. So it's not really a big thing so I haven't really received much help towards it. I went to a group, but I hate groups, I refused to go at the start and then they did talk me into it.* [Jennifer, service user]

> *Coming to terms with the diagnosis and the treatment was difficult for some people. One person was told by his psychiatrist that his illness wasn't something that could be*

*treated in hospital, but that every time he felt 'very low' he should take a Diazepam and to contact his GP.*

*There is a lack of support for me and my family at the moment in dealing with my personality disorder.* [Brian]

Clinicians recognised the potential difficulties for young people and families, with the shift in focus in terms of diagnosis and intervention, and the reduced involvement of, or support for the family:

*Even though they are adults, their illness is going to have a huge impact on their family, so that's a huge area. And I think in [Trust] the personality disorder service is very under resourced* [CAMHS Psychiatrist]

Another Psychiatrist in CAMHS, in a different Trust, suggested that Adult services offered less support for young people diagnosed with personality disorder than is available to them and their families in CAMHS. This psychiatrist suggested that, as such, it was important to manage young people's expectations in transition, if it is obvious that certain interventions or support might not be available for them:

*I think more generally there's an interesting thing about personality disorder, because I was involved in a case years ago where CAMHS were feeling that this person was down with attachment problems and had an awareness that adult services might say that this looks like personality problems, but we had been providing a lot of input and then, and indeed inpatient input, and adult services came along and though...they had a different perspective on it and said "this feels like personality". [ ] I think that one particular issue of personality disorder and attachment problems is a tricky issue, just that one specific one, because in general, personality disorder as a diagnosis is not reached in under 18s. There's a debate that it should be, we kind of think more along the lines of early trauma and attachment problems, and that's probably unfair, but I wonder if there's more resource for that for people in the CAMHS system than there might be in the adult services. For example, we were told by a Trust, [ ] that their adult services just simply didn't have access to psychology, there just wasn't any, and we raised the topic that this person might benefit from psychoanalytic psychotherapy in the longer term and the sense was that there was no chance, or if it was happening it's so far away it's not even worth thinking about. So, manage the expectations of the people coming through.* [Consultant Psychiatrist, CAMHS]

### Resources – the impact on young people

Service users and carers were aware of the pressure on resources within mental health services, particularly within adult services and inpatient care. Young service users discussed the *'huge caseload'* carried by their adult keyworkers and psychiatrists and acknowledged that such work pressure would affect the level and quality of adult service provision. The pressure on resources was used as an explanation for the reduction in duration, frequency and limit on the number of appointments they received, or expected to receive. There was a degree of resignation that compared to CAMHS support in AMHS would be limited. The potential impact of this perception on services engagement is worth considering. For some, the perceived pressure on services makes it a less accessible and a less available service, and as such would deter contact when crises arise:

> *I wouldn't even give them a phone call, if that makes sense. It just doesn't feel that if you make the phone call it will make a difference. To them, actions speak louder than words. If I said to them that I was going to commit suicide they'd just go, "well, have you planned it through, what you're going to do? Well then, do it." If I walked into the hospital and I was overdosing, I was dying, they would say "oh, he was serious; we should probably do something about that." It's not the doctors' fault, I don't think in any way, not the practitioners or any of the people's fault. It's higher up. They don't have that choice, they're so limited due to the amount of work they have. All the doctors that I have seen - they have all helped me as much as they could, to their level of work and stress and all that jazz. I'm surprised half the time that the psychologist doesn't have to go and see someone, because he's a stupidly busy man*. [Steve, service user]

In one of the Workshop Consultation groups, CAMHS staff suggested that their approach to such a crisis situation would be different from what they imagine it would be in adult services. CAMHS regard their service as more responsive and flexible in such situations:

> *And we would advocate even saying to the young person and the family, even if there is a crisis situation, if you're open to our services, phone our service rather than going to A&E or phoning the GP. But in the Adult Service, maybe this is a generalization, but I think that if there's crisis situation you would be told to go to A&E, whereas we would be trying to prevent people from going to their GP and A&E, trying to prevent that long and protracted wait where you can lift the phone, and if there's a possibility of seeing someone either the same day or the next day. And I think that is potentially something that's missing in Adult Services.* [CAMHS Practitioner]

The pressure, as surmised in the quote above, emerges *'higher up'* and the application of the pressure from management to address waiting lists and implement discharge policies was thought to have a significant effect on the mental health outcomes of young people:

> *Yeah, the official Trust policy is two cancellations and you're discharged, or two DNAs and you're discharged. I never discharge anybody because they've cancelled twice. If somebody comes up and they're not well or something's happening...but two DNAs and that's it, because my waiting list is massive and the pressure is intense and when I go back to my superiors and they say "Why aren't you taking more people on?" I say "well, because I'm at capacity." Then the first thing they're going to look at is DNAs and if I've got people on my caseload who have DNA-d three or four times they're just going to say that this person doesn't want to attend, it's time to discharge them. That's the way... because of the pressure on adult services that's the way it is.* [Clinical Psychologist, AMHS]

CAMHS practitioners appear to be less strict with regard to the Did Not Attend (DNA) policy, although the policy is the same across all services. When young people move from a service that adopts the approach described in the quote below, to a more clinical application of the policy, as described above, the level of disengagement is understandable:

> *The same DNA policy exists across all mental health services: When a client DNAs an appointment you are expected as a clinician to mechanically review all of the case notes, because there are people that NEED to be receiving the service. I would be asking the questions, if it was a case of two strikes and you're out, that's wrong, I would be asking did you ring the family, did you contact the social worker, did you contact the GP, have the family moved house, are they a travelling family, why has that child not come. Can they not read? We don't have a different policy, just maybe because of the type of relationship we have with some of the young people, the expectation is that if they DNA you lift the phone. Often it's the most vulnerable young people that will miss appointments, or the families with the most problems.* [Team Manager, CAMHS]

In an effort to cope with the waiting lists within CAMHS, a social worker described a request to consider reducing the number of sessions provided to young people. This plan was not implemented as staff felt they '*would not be providing the best for young people.'* Increasingly, the voluntary sector are often asked to bridge the gap:

> *I think there is a perception too that those services are over stretched, that the workers are doing the best they can in a system that really has not got a lot of flex in it. They're really overstretched. And that's sometimes why there is a gap- with the community and voluntary sector services trying to bridge [it], ( ), because the community and voluntary do have a bit more flex, so there's something about the system that doesn't support the workers.* [Counsellor, Community and Voluntary Sector]

The views of another manager and counsellor in the community and voluntary sector suggest that the lack of flexibility within systems does not always support the needs of the service user. She talked about the importance of building trust with young people, and how a prescriptive limit of six counselling sessions does not account for the time that might be needed to build up trust with vulnerable young people:

> *We don't have a time limit on our counselling service, you know, most agencies do, and certainly, where children are concerned, you're building up trust, to begin with. I had a wee client there recently where the first two sessions was a game of pool, [ ] but the fact that he was able to beat me, you know, play the game of pool and beat me, he was more open then to building up trust with me, because I was an adult and he wasn't going to trust... He'd been abused and he wasn't going to trust another adult. So that was two sessions gone, then you're back in the counselling room and you're starting building up trust, [ ]. So you couldn't restrict it to six sessions.* [Counsellor and Manager, CVS]

Other gaps and potential risk areas identified by those interviewed included the lack of, or shortage of psychotherapists within the mental health services in Northern Ireland; the shortage in clinical psychologists; staff shortages across the services due to sick leave or maternity or unfilled posts; and the crisis assessment procedure at hospital Emergency Departments. The latter was highlighted as being particularly problematic. The lack of privacy, the shortage of staff specifically trained in mental health, and the effect of waiting in a busy, general hospital environment for a long period were all raised as being problematic. Brian a service user who has presented at ED on a few occasions describes what it is like:

> *…you don't know where to go and your case is just being pulled and pushed about; you don't know where you stand. And then there's no set place for people with mental health issues to go, for adolescence or adult. So you're actually going into a busy hospital to sit around with your anxiety going, the voices in your head going, your hallucinations, the flashbacks, and it's all very raw and there's just no, what's the word for it, you just feel like you're not (...) in A&E emergency, you're more sort of something different, because A&E is more for physical you feel, and you don't feel like it's mentally covered, and then it's just waiting to get seen, waiting maybe a good four or five hours to be seen and then being sent home after with no support, because they come out, nurses come out instead of doctors, so they can't prescribe you anything or do anything to help you.* [Brian, service user]

Such a scenario, as described by Brian, is common according to this community worker, and poses significant risk for young people:

> *If you put in context, whereas someone presenting to A&E with a mental health problem, where they are placed in terms of urgency, and it's not very high, unfortunately. And much of the time, because of the current infrastructure, sadly, these people are left sitting in A&E departments and EDs with increased levels of risk, as opposed to lower levels of risk in terms of their mental health and wellbeing. We've had phone calls where we've had to go and talk people from bridges, we've had to phone police to trace young people and vulnerable adults who have walked out of A&E and who are going to kills themselves, with no follow up support.*
> [Manager, Community and Voluntary Sector]

### *The physical environment*

Another resource-related issue worth considering briefly is the physical environment that services are delivered in and through. The location of the clinic where the young person attended appointments, the state of the building, the décor, the layout of the room, and the overall atmosphere all mattered to a greater or lesser extent. Some young people felt exposed if the location of their appointment was in a dedicated mental health facility. One young woman talked about having to walk past her school to go to her appointment and being conscious of other pupils noting where she was going. Sitting in the waiting room for her AMHS appointment was, for another young woman, *'daunting'* and *'off-putting'* as she looked around the room and wondered '*is that going to be me in years to come?'* While the feelings attached to attending such mental health clinics or hospitals were generally on the negative side, another young person actually reported the opposite. Moving to AMHS meant her appointments were now in a mental health outpatient clinic as opposed to a general community hospital. In CAMHS she waited alongside other 'general' patients, fearing the receptionist would call out the reason for her appointment. In adult services she feels more *'comfortable'* in the knowledge that those around her are all there *'for the same thing.'*

> *The new building is lovely. I am in (AMHS Building), that's where I would go for all my appointments, and it's lovely to see somewhere that, as far as I can see, it's just for mental health. [ ] but it's just nice to see that there is genuinely somewhere for people with mental health problems to go, because when I was in CAMHS I would have been going to [General local hospital] It would have been a different room every time we went and it was almost like... you kind of felt that you weren't really supposed to be there, kind of thing. It was just nice to see that this is where we go and this is our place*

> *and it's nice that there's somewhere specific for people with mental health problems.* [Sally, service user]

Dedicated mental health venues were often in locations that required a bus, taxi, or car journey, and often carried stigmatising and negative associations. While one social worker, working primarily with young people around drug and alcohol problems, admitted that an out of town location can be awkward for young people, he also regarded their willingness to make the journey as a test of their commitment to the process. One community and voluntary group offered their *'young person friendly'* premises to other statutory bodies as an option to meet with young people who attend both services. The offer hasn't been taken up by mental health services as yet.

Making the environment comfortable, accessible and welcoming all make a difference according to those interviewed. Young people and parents talked about '*big formal buildings' 'crap buildings*', environments that are *'clinical'* and *'sterile.'* They referred to places that are '*isolating,'* that are '*not very nice'* are *'yuk,'* that have an *'obsession with beige, or magnolia walls,'* that have magazines dating to 2007, a TV with the news channel on, and where the waiting room *'is basically a corridor.'* Environments that were positively evaluated on the other hand were described as *'friendly,*' *'brand new*,' *'bright'* and *spacious'* with *'lots of glass and grass.'* They were places that you could *'buzz yourself in'* they were *'lovely', 'gorgeous'* with '*lots of trees.'*

> *The one we went to is just a little whitewashed building. So it's nice. [Kate, Parent]*

> *It doesn't seem like a place where there's going to be a lot of dark things talked about. It feels like you're going someplace where everything is safe and friendly. There's a good atmosphere [ ] you go in perfectly calm and leave even calmer.* [Ian, service user]

The notion of a *'safe space'*, particularly in relation to CAMHS, resonated with the accounts of others who described their experience in language that suggested CAMHS as a protective and sheltering environment. The layout of room, and the way it was used, was important to how a young person felt when attending services. Faced with two practitioners in formal dress on the other side of a desk was intimidating for one young person, while another found '*just two chairs facing each other, a small room, and a desk'* equally uncomfortable and the overall experience as '*not very appealing.'*

A practical point raised by two young people in different contexts was the need for a room, separate from the waiting room, where parents or young people could go if they needed space to compose themselves during, or after, a particularly difficult session. All of the above

contribute to the overall atmosphere and to the experience of attending mental health services. As noted the transition to AMHS is not necessarily associated with a move from a positive to a negative environment. Some preferred the AMHS environment. However, on the whole there was a sense that CAMHS offered a friendlier and more welcoming environment compared to AMHS:

> *When you went into CAMHS, it was almost like a younger atmosphere [ ] there's like a bit of friendly atmosphere, something about it. With then the adult one there's obviously like more clinical and it's for like an older age group. [ ] because the CAMHS building is just so – was more kind of, I don't know, friendly and bright and everything, but then that transition, it's probably just, (...) I don't know how to word it, but it was just more clinical or something or just something like, yeah, and because I was so young.* [Megan, service user]

### *5.6.4 Formal contracts and arrangements between the statutory and the community*

Representatives from fourteen community and voluntary organisations were interviewed. Some of the services provided by these organisations to young people were written into formal contracts with the statutory bodies, with some providing support on a regional basis or across two or three Trust areas. Other relationships were less formal and more organic in their development. The highest concentration of third sector organisations is located in the urban centres of the Belfast and Western Health and Social Care Trusts, with varying levels of community support across all other areas. While there was general acknowledgement from those interviewed in the statutory sector, of the value and necessity of these services, the community sector felt that their contribution to the economy of care was not fully recognised by the statutory. Alternatively, practitioners from the statutory sector indicated that they are not always aware of the relevant community and voluntary organisations, or knowledgeable about their remit and governance. Problems identified from both sides suggest that the links between services, the channels of communication, and the feedback loop and support mechanisms between the two sectors could be improved.

Staff interviewed within CAMHS and AMHS acknowledged that provision in the community and voluntary sector was sometimes more appropriate for a young person than statutory services, or could be usefully provided alongside it. Representatives from all sectors raised the importance of having a good understanding and knowledge of services. However, we found a general lack of awareness within statutory services about CVS service provision. We further noted that such services carry a level of uncertainty about their future and this engenders a sense of unreliability among statutory service professionals. The lack of clarity of service structures and roles was also apparent among CVS.

A consultant psychiatrist suggested that *'it can be quite difficult to keep up'* with the nature of services in the voluntary sector as *'things change quite rapidly in the community sector in terms of funding.'* This was a sentiment expressed by practitioners across Trusts who said it can be difficult to establish what services actually exist, or if they meet governance standards, before *'accessing and making use of them.'*

A social worker in a community and voluntary organisation for young people from a care background, and from disadvantaged communities, told how the link between CAMHS and her organisation *'was stumbled on'* and only happened after she completed a college placement with them. She added that while both services complement each other, their participation is *'down to good will'* as it is not resourced. She described how workers attend meetings with treatment teams and psychiatrists, providing an advocacy role for young people in relation to their mental health services. While this particular link with CAMHS is working, she believes *'there is a lack of knowledge of what different organisations and people are doing.' A* youth worker in a community organisation admitted that she *'did not have enough of a knowledge of all the complexities of both services [CAMHS and AMHS]'* and was not wholly familiar with the kind of support that young people she works with may be getting from mental health services.

The interface between CAMHS and AMHS on Transition Panels and meetings has provided a forum to share and learn about alternative sources of support that exist within the voluntary sector, and discuss their appropriateness in providing support for young people. Through the panels, CAMHS staff became more aware of such organisations and their remit, increasing the choice and options for young people leaving CAMHS:

> *It probably increases the choices too, that we have to go and discuss and go back to our young people and discuss what options are available, and ultimately if they still don't want to pursue that option, well, at that point in time that's their choice. But by having discussions with our colleagues we're even aware of other organisations that maybe are available, maybe not even direct mental health services but other voluntary organisations or whatever that are available within the adult world that we may not know about. So I think it actually broadens the choice.* [CAMHS Team Manager]

A conscious decision was made by CAMHS staff in the Belfast Trust to find out more about community organisations, to identify how they could work together and provide a level of supervision to community workers to support young people who perhaps did not meet the criteria for adult services. This transition from CAMHS to the voluntary sector reportedly works well but is not commissioned as such:

> *The difficulty we have is a lot of our young people at 18 aren't emotionally mature enough to transition into the Adult world and a lot of them don't fit, particularly those coming from the drug and alcohol (work) and those who we had concerns regarding personality disorders and stuff like that, [ ] So part of us ensuring seeing transitions over was we had to take on board that we needed to invest some of our time getting to know these organisations, getting to know the work they've done, and actually, although we're very small teams, we do have staff who offer some supervision in there as well, and that was the best way for us to find out how were we safely transitioning young people, and I think that has worked quite well, to various degrees, because we can then call on them and we can do things jointly together. But that's something we've had to do; it wasn't something we were commissioned.* [CAMHS Team Manager]

Practitioners from both the statutory and voluntary sector suggest that the communication, recognition, and trust between the two sectors are sub-optimal. A drug and alcohol addiction youth worker stated that while statutory services did refer young people to them, he felt the voluntary services were perceived to be not as skilled or as professional as the statutory services:

> *In terms of the perceptions and attitudes from some statutory service workers, there is definitely a skills perception that we're not skilled enough or professional enough to do the work sometimes, and that can come through in how they communicate with you, I think. I remember finding one lady very condescending, in particular.* [Youth Worker, Community and Voluntary Sector]

A manager in another community organisation, holding formal Health Trust contracts, said they felt they were *'being used rather than partners.'* He and others felt that their services were sometimes used to address breaches in the waiting lists within CAMHS. He felt that *'lip service'* was paid to the Compton and Bamford reports which advocated *'a mixed economy of care.'* This manager was not alone in recommending greater involvement of the voluntary sector in the multi-disciplinary, multi-agency discussions and processes, so that the best service and care can be provided for young people.

> *One of the things I would have loved to have done, [ ] would have been for us to go up to CAMHS and sit in on one of their threshold meetings to see how they actually decide [ ] about referring clients through to us. And the other thing is that CAMHS send out a letter at the same time they refer through to us, to the families, to say to them that we're referring through to Voluntary organisation and you will be offered x number of sessions. [ ] the expectation is raised that there is going to be an*

> *intervention provided, or it leaves it that if we're screening you know, the expectation is there that an intervention will be provided.* [Counsellor and Manager, Youth CVS)

The lack of trust or confidence that statutory services have in the voluntary sector is thought to stem from a general lack of knowledge. For example, a counsellor from a CVS organisation secured a formal contract to provide a service within the Trusts to young people (who self-harmed), it became part of a valued partnership working alongside GPs, community mental health teams, crisis teams and psychiatrists:

> *I think that setting up the (CVS) project as a service, which was the statutory and community working together in a partnership - that worked. And the statutory weren't afraid of the community and voluntary sector because they weren't good enough or weren't qualified enough – and that was ignorance more than anything else. Because given the length of time it took people even to refer into the (CVS) project when it was initially set up, it was a problem for statutory to refer in, even though they were instructed to refer in, but once that has happened and then five years after it's been running, they were like, look the project will be stopping because of the tenders, we'll give you two workers instead and the response was no, because we'd rather have the (named CVS project), because it's a good pathway and a good partnership between the statutory and voluntary sector, and GPs are in that loop, so GP to Psychiatry to community mental health teams, so there's a link, and even the family support service, they're not in isolation of a GP or a community mental health team, so there's a link, there's a connection (that) runs the whole way through.* [Counsellor, CVS]

Similarly, a manager in a community and voluntary organisation working with young people coming out of care or at risk of homelessness, told how relationships with CAMHS has improved when both attended family hub meetings. Being present at these meetings and informing the hub members of their service led to an increase in referrals from CAMHS. It also meant that, due to the development of personal relationships, her telephone calls no longer went unanswered at CAMHS:

> *From meeting the individual CAMHS workers at those meetings, that has meant I can pick up the phone now and those workers will take my call [ ] at the start, you might have rang for weeks and the worker might never have returned your call. [ ] Now, they understand what we do and they're making referrals and they can see, I believe, the difference we are making. They're really ready to pick up the phone, answer the phone and work with us, and are, I find, quite respectful now of what we do, whereas before they just didn't understand what we did.* [CVS manager]

The same relations do not exist with the staff in adult psychiatry, however. In their efforts to support a young person who was finding the transition into adult services very difficult, the same organisation contacted the adult team on behalf of the young person, but were, according to the manager, told they *'did not understand' how [adult service] works.'* The adult mental health team were subsequently invited to make a presentation to their community organisation, so they might understand the service better (something which at point of interview had not happened).

There is clearly evidence of good practice and interagency work between the statutory and voluntary sector providing care for young people who are making the transition out of child and adolescent mental health services. Greater awareness and knowledge of the services provided across both statutory and community sector increases the options and choices of care available to young people, and perhaps offers a more holistic package of care.

Concerns about funding and sustaining services within this sector were, however, frequently mentioned issues that have the potential to undermine the contribution and role of the voluntary sector, and the support they provide to young people and indeed to the statutory service:

> *And what I would say to the department is, and hopefully through the Protect Life strategy [ ] they'll commission those high quality service providers across Northern Ireland who are providing essential services, because without the voluntary community sector, the A&E is in a bit of disarray at the minute, the statutory sector could not cope without those supports that are available within the voluntary and community sector, and not just talking about funding I'm talking about those services available 24/7. The social return on investment the voluntary and community sector brings to this field of work is exemplary.* [Manager, Community and Voluntary Sector]

## 5.7 Chapter 5 Summary

- Eighteen service users took part in individual qualitative interviews during the transition from CAMHS to AMHS; ten of these were re-interviewed following the move to AMHS, as were an additional 7 service users who had been in the care of AMHS.
- Twelve parents/carers were interviewed on a one to one basis; an additional five parent/carers took part in a focus group interview.
- Twenty six service providers, from both CAMHS and AMHS were interviewed individually.
- Thirty two of the 42 participants at a Workshop took part in one of four focus groups
- Most of young people interviewed accessed CAMHS via the GP, and all received an initial appointment within days or a 'few weeks.'

- **Experience of CAMHS:** Young people valued a service that was trustworthy, accessible, and responsive. Confidentiality was an important aspect of care.
    - Relationships with CAMHS staff were generally rated as positive, service users valued relationships that were understanding, non-judgemental and authentic/real.
    - 'Being listened to' was a key aspect of care for both service users and parents/carers.
    - Problematic aspects of care included; high staff turnover; a sense of not being listened to or consulted; and clinicians' poor interpersonal skills.
- **Expectation of AMHS**: Some YP believed AMHS would meet their mental health needs better than CAMHS; that it would give them more autonomy; and provide greater confidentiality.
    - Service users and parents/carers expected fewer resources in AMHS, a busier service with longer waiting lists; with an emphasis on medication, and one that is designed to cater for more seriously ill people.
    - YP are poorly informed about the nature of the service in adult mental health; their expectations and knowledge is often based on hearsay and popularly held stereotypes.
    - Staff in both CAMHS and AMHS acknowledged information gaps about each other's service.
- **Moving On:** Coinciding life events/changes make the timing of the transition to AMHS more difficult for some YP.
    - Developmental readiness, emotional and intellectual maturity may mean young people need more intense or different care than that provided in AMHS at 18.
- **Experience of Transition:** Most young people anticipated the move to AMHS in negative terms. YP expressed a feeling of being rejected, or pushed aside during transition.
    - Both service users and parents/carers expressed feelings of anxiety, fear and sadness during transition.
    - Service users and parents/carers expressed concern that they would be excluded from the decision making process.
    - The lack of family therapy in AMHS was a source of concern for all service users, parents and clinicians.
    - The gap between appointments was cited by young people as one of the worst aspects of the transition process
    - Joint meetings rarely happened.
    - The nature of, and content of information relayed to service users about AMHS was wholly inadequate.

  - AMHS staff reported unhelpful delays in the transfer of notes from CAMHS to AMHS
  - Some parents/carers welcomed the fact that they would no longer have sole responsibility for their child.
- **Experience of AMHS:** The frequency and duration of appointments were two of the most consistently mentioned differences between CAMHS and AMHS.
  - Some young people welcomed the move to AMHS and the autonomy it gave them.
  - Young people reported a reluctance to disclose the full nature of their mental health problems for fear of being admitted as an inpatient. Greater stigma is attached to adult mental health services compared to CAMHS.
  - Confidentiality in AMHS enabled some young people to disclose previously undiscussed issues and problems.
- **Understandings of Recovery:** The meaning of recovery for many amounted to 'living a normal life,' in line with a social recovery model.
  - Recovery was defined as the absence of mental illness and discharge from mental health services.
  - Recovery needs to be goal related; young people valued an outcome focussed programme. Achieving outcomes and setting goals was an important component of the recovery journey and engagement with services.
  - Recovery for young people is about regaining control, developing agency and experiencing empowerment.
- **The Nature of Relationships:** Core themes identified on the nature of relationships with mental health services include communication, bonding and connecting, equity and power, the role of carers, and other sources of support.
  - Being able to talk openly and honestly, and to be listened to in a therapeutic environment was highly valued.
  - Being respected, being shown empathy, experiencing connection and care, and being given time and consistency were likewise valued.
  - Service users were critical of mental health staff who intimidated, patronised, invalidated or judged them.
- **Role of Carers:** Parents, mothers in particular, supported young people by bringing them to and attending appointments, administering and monitoring medication, monitoring risk, attending inpatient facilities and arranging private therapy.
  - Parental involvement in young person's care reduced significantly with transition to AMHS.

- **Other Sources of Support:** Half of young people interviewed received support from community and voluntary organisations in addition to that from statutory mental health services. Some availed of school counselling services.
    - YP used social media and the internet for support and information about their mental illness and problems.
    - Friends were seldom identified as a source of support in relation to mental health problems.

## CHAPTER 6: STAGE 4 RAPID EVIDENCE REVIEW

In the original protocol for this study, a Critical Interpretive Synthesis (CIS) was proposed whereby all types of studies on a subject, regardless of quality, can be included within the process. The process allows for samples of papers to be selected from a larger pool rather than review all papers. The CIS process, whilst sensitive to the process of a systematic review, is more iterative process allowing for refinement of the review questions as the review progresses. However, given the breadth of the topic area, and the recent publication of NICE (2016) guidance on the transition from children's to adults' services and a number of systematic reviews on the subject of transitions from children's to adult mental health services (Embrett et al. 2015, Paul et al 2014; Mulvale et al 2016; Reale and Bonati 2015), a more pragmatic approach was adopted.

The approach employed a modified version of the review of reviews approach (Fullerton & Burtney 2010) to assembling evidence. Using this approach the primary source of evidence for the review was studies included in high quality systematic reviews. Systematic review procedures were used to locate, select, and critically appraise the located systematic reviews and primary studies. The primary studies included within the systematic reviews were used as a core source of data and were collated in tabular format for a narrative analysis. Additional searches were carried out to locate other primary studies relevant to the review questions. Studies not included in previous reviews were subjected to relevance and critical appraisal, and combined with the other primary studies in the summary tables. As part of quality assurance procedures, and to reduce the risk of bias, once all the studies had been collated, studies were selected at random and assessed for methodological quality by a second member of the review team.

### 6.1 Aim

The aim of this review is to present a critical synthesis of the international and national research evidence on the transition from CAMHS to AMHS. This review presents a synthesis of the research evidence on the transition from CAMHS to AMHS, focusing on three key review questions.

**Review Question 1 (RQ1)** What are the main messages from policy, best practice or guidance documents on the transition from CAMHS to AMHS? What are the features of an 'ideal model' for the transition from CAMHS to AMHS?

**Review Question 2 (RQ2)** What is needed? What does the literature tell us about the transitions from CAMHS to AMHS?

a. How are transitions experienced by young people?
b. How are transitions experienced by parents/carers?

c. How are the transitions experienced by service providers?

**Review Question 3 (RQ3)** What works? What is the evidence of the effectiveness of different approaches to supporting the transition from CAMHS to AMHS?

a. What approaches or models of care have been used?
b. How has the effectiveness of approaches been evaluated?
c. How do the approaches meet the principles of best practice (RQ1) and the needs of young people, parents/carers, and service providers (RQ3)?

## 6.2 Methods

Given the scope of the three research questions, different search strategies and review procedures were used.

### *6.2.1 Search strategy and inclusion criteria (RQ1)*

For the review question the main source of evidence was guidance and best practice documents from the UK. Electronic databases were searched to identify standards or guidance using the following keywords (transition OR transfer OR interface) and (guidelines OR guidance OR standards OR best practice) AND (mental health OR CAMHS OR AMHS) AND (Young People OR Adolescen* OR Teen*). Additional based searches were conducted and free text searches using Google Scholar.

To be included in RQ1, papers/documents must provide guidance, summaries of best practice for the transition from CAMHS to AMHS. In order to locate best practice within the UK context, this review question limited the literature to guidance and best practice from the UK only.

### *6.2.2 Search strategy and inclusion criteria (RQ2 & RQ3)*

For the RQ2 and RQ3 the focus was to identify review-level evidence and more recent primary research describing (a) the experience of transition from different perspectives of young people (service users), parents/carers or service providers or (b) the evidence of the effectiveness of different approaches to supporting the transition from CAMHS to AMHS. A systematic search strategy was used to identify both reviews and primary studies on the subject of transitions from children's services to adult mental health services. Within the population of young people transitioning into adult mental health services, 4 key population sub-groupings were identified relevant to the review: young people mental illness/disorder; young people with Attention Deficit Hyperactivity Disorder (ADHD); young people with Autistic Spectrum Disorder (ASD); and young people with eating disorders.

For review question 2 and 3, extensive and systematic searches were conducted to identify the relevant literature. Searches were conducted using electronic databases (presented

alphabetically): ASSIA, British Nursing Index, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Cochrane Library and Database of Abstracts of Reviews of Effectiveness (DARE), Embase, Journals@OVID, Medline, PsychINFO, Pubmed, and SIGLE.

Each database was searched using database-specific keywords, variants and truncations, to cover transitions from CAMHS into adult services among young people with 4 conditions: mental illness/disorder; ADHD, ASD and Eating Disorder. Search terms also include included: transition or transfer or continuity of care; 'children's service' or 'CAMHS' or 'adult service'; experiences OR views OR evaluation OR effectiveness; 'models of care' OR 'service development'; policies or protocols or care plan. Additional searches were conducted of the grey literature and email requests sent to key experts. Hand searches of key journals were conducted, and the reference lists of identified reviews were manually searched for additional relevant reviews and primary studies. Ancestry and forward searches of references of studies included in reviews were conducted using Google Scholar.

Databases were supplemented with searches of the websites and contacts with key experts. Full citation searches using Google Scholar and Scopus were conducted on all key papers. Email requests for information were sent to key informants. All the retrieved studies were stored on a shared folder and bibliographic details including main keywords were entered into the Endnote bibliographic software package for ease of management.

Eligibility criterion included reviews or primary research published from 2004 onwards reported in the English language with a focus on the transition from children's services to adult mental health services. Letter and opinion papers were excluded from the main review. No country exclusions were applied, and no exclusion criteria based on the research design (e.g. survey, qualitative study, secondary analysis or experimental design) were set.

The searches were initially conducted in January 2015 and updated in August 2016. Titles and abstracts were assessed for relevance by one member of the team (DF). Full text (paper or PDF) for relevant reviews and primary studies were obtained and screened for both relevance and quality by two members of the team (DF/SMG).

### *6.2.3 Quality assessment procedures*

Two different assessment procedures were used to assess the methodological quality of the research studies: one for review level evidence and a second for primary level effectiveness studies.

#### *Assessment of systematic reviews and scoping reviews*

All relevant systematic reviews and scoping reviews were subjected to the quality assessment procedures. In order to assess how well the review was conducted; the methodological quality

of each review was assessed using a modified version of the AMSTAR tool (Shea et al. 2007) and procedures used by other reviewing organisations (e.g. National Institute of Clinical Excellence (NICE)). In order to identify potential risk of bias in the review, each paper was assessed on: (a) its search strategy; (b) the relevance criteria for inclusion; (c) the quality of included studies; (d) the procedures for assessing the quality of the primary studies; (e) the method of synthesis, and (f) the presentation of the data. Each review was allocated a score for each question (score of 1 if sufficient evidence is presented and score 0 if not described or insufficient information presented). The total score was calculated to grade the strength of the review (Score 6 or 7=Strong methodology, Score 5 or 4 = Moderate methodology, and less than 4 = Weak methodology).

#### *Assessment of primary studies*

Given the wide inclusion criteria for the individual studies, new studies were assessed for methodological quality using a modified version of the critical appraisal tool developed by Hawker et al. (2002), the tool used by Paul et al. (2014) in their systematic review on transitions. The tool uses a scoring system covering 9 components of critical appraisal including components on aims, methods, sampling, analysis, ethics and bias, findings, transferability/generalisability, and implications for practice. Each study was given a score 1 (poor) – 4 (good) for each component, generating a maximum potential score of 36.

### *6.2.4 Data extraction*

Data extraction involved different approaches depending on the research question and data source.

#### Review Question 1

For policy and guidance papers, each of the key messages relevant to the transition from children's to adults' services, were summarised in a table grouped by theme. As this body of literature included government policies, consensus statements, as well as formal guidance/guidelines, no assessment of methodological quality was undertaken. The data extraction process, using the summary tables, aimed to identify consistent features or elements important for the transition from CAMHS to AMHS

#### Review Questions 2 & 3

For the systematic reviews, as part of the critical appraisal process data were assessed for quality. Once included within the review (rated as good or moderate quality), further details on the review were extracted into tabular format. This included: the focus of the review (e.g. mental health, ASD, ADHD, eating disorder); number of papers included in the review; key findings (see Appendix 9 Table 1).

A second data extraction sheet was developed to summarise each of the individual primary studies included in the systematic reviews or located in subsequent searches. The summary tables included details on: author/year of study/country; the study focus; the study aim; research population (e.g. young person; parent/carer; service provider); design and sample size; the intervention (if describing an approach/model), findings/outcome measures, quality assessment score, and additional comments. Data were systematically extracted into tabular format by an individual project team (DF) and verified by one other project team member (SMG). Please note, if the primary study had not been subjected to quality assessment in one of the included systematic reviews, the research team conducted an independent assessment of quality (using the procedures described above), otherwise the original grading from the source systematic review was used (See Appendix 9 Tables 1-4).

### *6.2.5 Data synthesis*

Given the inclusion of different study designs each with a different focus, a meta-analysis of the findings is not possible. A summary of each of the primary studies included within the systematic review(s) were summarised in tabular format, grouped by population group (e.g. service user, parent/carer or service provider) and by condition (e.g. mental illness, ASD, ADHD, eating disorder). A narrative synthesis is provided for each summary table.

For Review Question 3 given the dearth of robust experimental studies, all study designs including less rigorous designs, were also included to draw out the key messages on the benefits, or otherwise, of adopting different approaches or models of care to improve the transition process.

### *6.2.6 Limitations*

As with any research, there are limitations to this review. This review aims to present an overview of the key messages on the transition from CAMHS to AMHS. Whilst this use of systematic reviews as the main source of research evidence permits a rapid assessment of the available evidence, the reliance on systematic reviews alone has limitations. Some of the evidence presented in the reviews has been highly processed, which means it is not always possible to present details on the study or to draw out clear messages for practice. In addition, even though the reviews were assessed for quality, review authors have adopted different inclusion criteria (e.g. some authors only focus only on research describing the experience of transition; others examine research on the experience of the transition as well as the evidence of the effectiveness of different models), and employ different critical appraisal procedures (e.g. some have very critical appraisal procedures, others are more inclusive). However, as described in 6.2.4, above, in order to minimise bias, data from all primary studies (those included in reviews and those located in subsequent searches) were extracted (and checked

for accuracy) onto tables, and a separate synthesis of the evidence was conducted. In addition, whilst every attempt has been made to locate all relevant papers (review level evidence, guidance documents, and relevant outcome evaluations), much of the literature on the transition from CAMHS to AMHS consists of descriptive studies which limit the ability to provide conclusive evidence for the effectiveness questions.

It is also important to note that the reliance on reviews as the main source of evidence can result in an over-emphasis on evidence from research conducted outside the UK (e.g. USA and Canada), which make it difficult to generalise the characteristics of effective interventions to a Northern Irish setting with a different healthcare system. To address this limitation, where possible, we present a particular focus on UK research and supplement any research gaps with evidence from outside the UK.

### 6.3 Results of searches & quality assessment procedures

Twenty one reviews were located. After the quality assessment, five were excluded (four had a focus on transitions to adult service but did not have a focus on mental health; one had a focus on mental health but not on transition). After quality assessment procedures, 6 of the reviews assessed to be of high to moderate quality which constituted the core reviews for review questions 2 and 3. The remaining fifteen reviews were included to provide additional information. After quality assessment procedures, a total of 15 reviews were eligible for inclusion in the review: ten focused on transition of young people with mental illness; one had a focus on all transitions from children's services but also included mental health; one focused on young people with ADHD; one focused on young people with eating disorders; and the remaining two had a focus on young people from a care background.

Table 6.1, below, presents an overview of the numbers of papers located, if subjected to relevance checks and assessment of methodological quality, and where the findings are presented in the report.

**Table 6.1**: Breakdown of located papers & where included in report

| Type of study | Relevance and quality checks | Numbers included | Where findings are presented in report |
|---|---|---|---|
| Background papers | Not quality assessed | Background | Chapter 1 Introduction |
| Guidance or best practice papers | Assessed for relevance but not quality assessed | Included (n=12)<br>Excluded not UK (n=13) | Chapter 6<br>Review Question 1 |
| Reviews | Assessed for relevance and quality | Total n= 21<br>Included as Core review (n=6)<br>Included as background reviews (n=10)<br>Excluded (n=5) | Chapter 6<br>Review Question 2 & 3 |
| Primary studies with YP, parents/carers, service providers | Assessed for relevance and quality | Included (n=31) | Chapter 6<br>Review Question 2 |
| Primary effectiveness studies | Assessed for relevance and quality | Included (n=15) reporting on 9 different approaches to transitions | Chapter 6<br>Review Question 3 (Effectiveness review) |

## 6.4 Review Findings: RQ1 National and local guidance

As described above, the individual papers from each body of literature were assembled in a tabular format and synthesised in a narrative format. The findings from each review question are presented separately before providing an overview of the key questions.

This section also provides a brief summary of key NI policy, guidance and practice with relevance to the transition from CAMHS to AMHS, and presents an overview of the key messages from relevant UK policy and guidance documents on the transition from CAMHS to adult services

### *6.4.1 Key Northern Irish policy and guidance*

Chapter 3 (Service Mapping) has provided an overview of the structure of CAMHS service in Northern Ireland. In this section we present a brief overview of three key reports (The Bamford Review (2008), The McCartan Report (2007) and the RQIA (2011) Independent Review of CAMHS) which have informed policy and practice in Northern Ireland. Each review outlines important recommendations for the improvement of the transition process (See Appendix 2 for further detail).

- **The Bamford (2006) review 'A Vision of a Comprehensive Child And Adolescent Mental Health Service' and DHSSPS (2009) Delivering the Bamford Vision: Action Plan 2009-11)**

The report contained 51 recommendations, of which a number relate directly to the transition from CAMHS to AMHS. It recommended that care pathways and protocols be developed to ensure optimal patient care between CAMHS and adult services. In addition, the review identified that the transfer to adult services usually occurs around the young person's eighteenth birthday. It recommended that flexibility is required to ensure the best interest of the young person is considered. The review also indicated that effective collaboration between adult and CAMHS will also ensure that the mental health and any other relevant family circumstance will be considered

**Box 6.1**: Bamford Review Recommendation 23 on the CAMHS and AMHS interface

| |
|---|
| ***Bamford Review Recommendation 23*** The interface between CAMH services and adult mental health must be addressed and more effective collaborative arrangements established to ensure that the suffering in a child or parent does not go undetected or untreated (Paragraph 6.11) |

- **McCartan Report (2007) Final Report of Independent Review Panel of the Eastern Health and Social Services Board**

The McCartan Report was prepared in response to a complaint by Mr and Mrs McCartan regarding the death of their son, Danny McCartan in April 2005. The investigation panel examined the treatment and care offered to Danny McCartan and his family and identified 12 key areas for improvement. A significant finding in the McCartan report was the poor transitional arrangements for young people moving into adult mental health services. It also highlighted that patients were not always engaged in the process or involved in the decisions surrounding transfer.

- **The Regulation and Quality Improvement Authority (RQIA) (2011) Independent review of child and adolescent mental health services (CAMHS) in Northern Ireland**

In 2010 a review of CAMHS in Northern Ireland was conducted by Regulation and Quality Improvement Authority (RIQA 2011). The review examined the quality and availability of a range of services and professional groups involved in the delivery of specialist mental health care for children and young people in hospital and community settings. The RQIA review team examined 2 themes with relevance for the transitions from CAMHS to AMHS: the quality and safety of care of young people admitted to adult wards; and the quality and safety of existing transitional arrangements between CAMHS and adult service.

The RQIA review team concluded that while progress had been made since the Bamford Review (2006), additional action was required to ensure that children and young people with mental health needs are seen by the right person at the right time in the right place. It made 5 recommendations on the transition from CAMHS to AMHS (see Box 6.2 below)

**Box 6.2**: RQIA recommendations relevant to the transition process (original numbering)

***Recommendations for the Health and Social Care Board (HSCB)***
1. Investigate and address the high combined 'Did Not Attend' rate and cancellation rates.
2. Routinely measure service user and carer experience and outcomes using consistent methods across all trusts.

***Relevant regional recommendations for trusts (original numbering)***
1.Young people and parents should be included in the processes of planning, delivering and evaluating services
7. Information provided to children and young people about the range and scope of services should be clear, concise and easy to understand.
21. Operational protocols should be in place for the seamless transfer of young people from CAMHS to adult services. There should be routine evaluation of how these arrangements are working, ensuring that the views of the young people are collected and considered.

The Bamford report recommended the reorganisation and expansion of the CAMHS model to move towards a more integrated CAMHS, bringing together children's care in health and social

care within one single system. Using such a model, CAMHS would operate partnership with children's services in other agencies, particularly education, youth justice, community and voluntary sectors. The DHSSPS (2009) *Delivering the Bamford Vision* is one of central policy drivers to implement the recommendations from the Bamford Report.

Some of the Bamford recommendations have been integrated within two key documents. The DHSSPS (2012) *Service framework for Mental Health and Wellbeing* sets standards aimed at improving the overall mental health and wellbeing of the population, as well as reducing inequalities and improving the quality of health and social care for people with mental health needs in NI. *Standard 31* (see Box 6.3 below) is specifically aimed at children and young people who are transitioning from child to adult services. *Standard 56* addresses those with learning disabilities and mental health needs. It highlights that people with learning disabilities are four times more likely to experience mental health issues and access to information and services requires improvement. This standard also outlines a multi-disciplinary approach to meeting the needs of those with dual diagnosis (learning disability and mental illness).

The DHSSPS (2012) *Child and Adolescent Mental Health Services: A Service Model* presents a stepped care service model for CAMHS (described in Chapter 3). The model acknowledges the importance of interfaces with other services including adult services, child care services, social care services, and external agencies (e.g. youth services, education, community and voluntary services), and recommends the development of protocols for all interfaces including adult services.

The role of the community and voluntary sector is also recognised in the *Making Life Better* document (PHA, 2014), with one of the key government aims '*to ensure a vibrant and sustainable voluntary and community sector that can thrive and work closely with Government in the design and delivery of policy and services in the interests of the people of Northern Ireland,' p31* '*in enabling and empowering people to improve their health, and in representing and supporting particularly vulnerable interest groups'*.

**Box 6.3**: Relevant Standards from the Service Framework Standards (2011)

**Service Framework Standard 31**

'A young person approaching their 18th birthday (between 3–6 months) receiving treatment and care for a significant health problem from CAMHS or a Paediatric service should be assessed, their need for services identified and where appropriate, arrangements should be made for transition to adult services. These arrangements should be made in partnership with the young person and their family/carers' (DHSSPS 2012 p.26.)

In a recent review of Northern Ireland policy and legislation, Kelly et al (2014 pg 52) synthesised 6 guiding principles that can inform transition practice.

1. Person-centred approaches to care focused on the strengths and aspirations of the individual rather than medical models of impairment;
2. Inter-agency collaboration and inter-departmental working;
3. Access to local and community based services with a focus on social inclusion;
4. Systemic approaches based on a 'whole child' approach;
5. Stepped models of care and service provision incorporating preventative, universal supports, combined, when necessary, with specialist provision for those who need it;
6. Participation of service users in decisions affecting their lives.

(**APPENDIX 2** provides a summary of other relevant legislation, policy and strategy documents).

### *6.4.2 Key features from guidance documents on the transition from CAMHS to AMHS*

Over the past decade there has been a proliferation of documents providing guidance on the transition from children or adolescent service into adults' service. Our searches identified 25 documents. Box 6.4, below, lists some of the key UK documents. Guidance documents from outside the UK were excluded from this stage of the review due to the different policy frameworks and health service systems.

**Box 6.4**: Key documents (sorted alphabetically) providing guidance on or summaries of best practice for the transition from children's to adult services in the UK.

| Author (Year) Country | Title |
|---|---|
| Department of Health & DCSF(2008a) | 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 |
| Department of Health & Department for Education and Skills (2006) | Transition: getting it right for young people. Improving Transitions of Young People with Long term conditions from children's to adult health service |
| Joint Commissioning Panel for Mental Health JCPMH (2012) | Guidance for commissioners of mental health services for young people making the transition from child and adolescent to adult services Vol 2. |
| National Institute for Health and Clinical Excellence (NICE) (2013). | Attention Deficit Hyperactivity Disorder: Diagnosis and Management of ADHD In Children, Young People and Adults. |
| National Institute for Health and Clinical Excellence (NICE) (2009). | Borderline Personality Disorder: The NICE Guideline on Treatment and Management. |
| National Institute for Health and Clinical Excellence (NICE) (2016). | Transition from children's to adults' services for young people using health or social care services |
| NCB (Kane 2008) | Managing the Transition from Adolescent Psychiatric In-patient Care Toolkit. |
| NMHDU/NDSS/SCIE Appleton and Pugh (2011) | Planning health services for young adults improving transition: a resource for health and social care commissioners. |
| Royal College of Nursing. RCN (2004) | Adolescent Transition Care – RCN Guidance for Nursing Staff. |
| Royal College of Psychiatrists Scotland (2013) | Attention Deficit Hyperactivity Disorder (ADHD) Guidance for Transition from Child & Adolescent Services to Adult Services |
| SCIE (2011) | Mental health service transitions for young people |
| Young Minds (Parker et al. 2011) | Transitions in Mental Health Care – A guide for health and social care professionals on the legal framework for the care and treatment of young people with emotional and psychological problems during their transition years |

The messages from guidance documents and best practice (Box 6.4 above) for transitions from children's services to adult services, and integrating the key recommendations from Bamford (2006), the McCartan Report (2007), and the RQIA (2011) review, have been combined in a composite model comprising the key features of the ideal transition was prepared (Boxes 6.4a-6.4c). The tables collate the features of 'ideal service,' where transition is viewed as a process rather than an event. The features described in the documents fall into three main themes:

- The overarching ethos and principles underpinning the transition (Box 6.4a).
- The transition process (Box 6.4b); and
- Transition review procedures (Box 6.4c).

An additional theme emerging from the more generic guidance is the importance of young people friendly services (see Box 6.4d).

**Box 6.4a**: The ethos and principles underpinning the transition from CAMHS to AMHS

| Theme | Feature | Source |
|---|---|---|
| **Ethos and principles of positive transition** | **Based on human rights and equality –** the young person's right to services | UNCRC (1989)<br>Bamford (2006)<br>Lundy et al (2012)<br>DHSSPS (2012 |
| | **A prepared transition – timely preparation** | McDonagh & Viner (2006)<br>DH & DES (2006)<br>Lamb et al (2008)<br>DHSSPS (2012) |
| | **An enabling process -** the young person is educated and prepared for adult services. This process involves skills development in communication, decision making, problem solving, assertiveness, self care, self determination, and self advocacy. | McDonagh & Viner (2006)<br>SCIE (2011) |
| | **Person centered –** the transition process identifies the wishes and aspirations of the young person (inclusive of parent/carer where appropriate) | NICE (2016)<br>DHSSPS (2012)<br>UNCRC (1989)<br>Lamb et al (2008) |
| | **Participative -** involves the young person, parent /carer (where appropriate) and advocacy organisations | McDonagh & Viner (2006)<br>NICE (2016)<br>UNCRC (1989)<br>McCartan (2006)<br>SCIE (2011) RQIA (2011)<br>Kane (2008)<br>Parker et al (2011)<br>DH&DCSF(2008a)<br>Kelly et al (2014) |
| | **Developmentally appropriate and strengths based.** | NICE (2016)<br>Kane (2008)<br>Parker et al (2011)<br>DH&DCSF(2008a)<br>Kelly et al (2014) |

**Box 6.4b**: Important features of the transition process

| | Features of process | Source: |
|---|---|---|
| **Transition process** | **Flexibility in timing -** seeing transition as a process with flexibility in moving to adult services depending on readiness<br>Agree a policy on timing of transfer – based on developmental readiness rather than chronological age – with flexibility depending on the needs of the young person | NICE (2016)<br>RCN (2007)<br>DH & DES (2006)<br>Kane (2008)<br>Parker et al (2011)<br>DH&DCSF(2008a) |
| | **Transition planning –** the transition should be planned between CAMHS and AMHS with at least one face to face transition meeting with adult service | NICE (2016)<br>Lamb et al (2008)<br>RCPCH (2003)<br>NICE (2013)<br>Kane (2008)<br>Parker et al (2011)<br>DH&DCSF(2008a) |
| | **Written plan –** a written individualised transition plan & care pathway created with the young person & parent/carer, and reviewed on regular basis.<br><br>Working closely with other agencies to ensure that the transition plan is incorporated into a young person's broader plan for young adult life (e.g. education/training/housing/work) | NICE (2016)<br>McDonagh & Viner (2006)<br>Lamb et al (2008)<br>DH&DES(2006)<br>Bamford (2006)<br>RQIA (2011)<br>Parker et al (2011) |
| | **Coordinated –** the experience of a coordinated and smooth progression of care. Ensure multi-agency working, co-ordination and accountability. Ensure primary care involvement. | NICE (2016)<br>DH(2008a)<br>Lamb et al (2008)<br>DH&DES(2006)<br>RQIA (2011)<br>SCIE (2011)<br>Kane (2008)<br>Parker et al (2011)<br>Kelly et al (2014) |
| | **Key worker or transition workers -** as a core component of person-centered care for the young person to:<br>• help to negotiate the multiple services that a young person may need to access during and after the transition;<br>• act as advocate for young people;<br>• put the young person in contact with peer support<br>• help the YP to develop self-advocacy skills<br><br>The named worker should ensure that the young person is offered support with the following aspects of transition, if relevant for them (which may include directing them to other services): education and employment; community inclusion; health and wellbeing; independent living and housing options (NICE 2016) | NICE (2016)<br>DH & DCSF (2008a/2008b)<br>McDonagh & Viner (2006)<br>DH&DES(2006)<br>Lamb et al (2008)<br>Parker et al (2011) |
| | **Cross-boundary working -** to ensure that the young person is placed at the centre of care system including GP, voluntary sector, social services, education etc. Build local **systems** to support transition. Identify champions. | NICE (2016)<br>DH (2008) DH (2010)<br>SCIE (2011)<br>Kane (2008)<br>Lamb et al (2008)<br>Parker et al (2011) |
| | **Continuity of care** – diagnosis and management of condition should be reviewed throughout the process, and there should be clarity as to who is the lead clinician. | DH (2004)<br>NICE (2013)<br>RQIA (2011)<br>SCIE (2011) |

| | Features of process | Source: |
|---|---|---|
| | (Use modified version of Care Programme Approach (CPA) linked with the Common Assessment Framework (CAF) in England or FACE approach in Northern Ireland to plan transition SCIE 2011)[12] | |
| | **Written protocols –** to ensure transition is robust and all services work together. Such protocols should be jointly agreed by all services, and include transition arrangements if YP not going to AMHS but requires ongoing support or YP transitioning to voluntary/private organisations. | DH&DCSF(2008b)<br>McDonagh&Viner (2006)<br>Lamb et al (2008) |
| | Operational procedure and funding (Kane 2008) | RQIA (2011) |
| | Inform service commissioners of gaps in service and of their responsibility to commission new services where resources are lacking. | Bamford (2006)<br>Kane (2008)<br>Parker et al (2011) |
| | Supported by trained staff - joint training<br>(including training in ASD, ADHD & eating disorders) | Lamb et al (2008) |
| | **Information sharing –** excellent information transfer following the service user (taking into consideration the young person's wishes regarding confidentiality). | McDonagh&Viner (2006)<br>RQIA (2011) |
| | Consistent information technology systems to ensure appropriate sharing of information. | DH&DES(2006)<br>SCIE (2011) |
| | Provision of summary of information in accessible and portable format | Parker et al (2011) |
| | Young person's personal folder (NICE 2016) | NICE (2016) |

Overall, the key messages from policy and guidance documents on the characteristics of a good transition process in mental health services include: a flexible process, centred on the young person, based on their needs, reflecting the developmental readiness of the young person; a planned process which identifies the young person's wishes and aspirations; with written plans and a keyworker to assist with the transition; supported by protocols and coordinated cross boundary working (working closely with other agencies to ensure that any plan is incorporated into a young person's broader transition plan for young adult life); supported by staff who are trained in adolescent health; and with information sharing taking account of the young person's wishes for confidentiality.

Box 6.4c, below, details some of the important features of the audit and review procedures of the transition process. Reflecting the principle of an 'enabling process', a number of service guidance documents (SCIE 2011; DH 2011; Parker et al 2011; NICE 2016) highlight the importance of involving young people and carers in the design and review of services. Also of note, the Refocusing the Care Programme Approach (CPA) (Dept of Health 2008b) in England, emphasises the importance of involving children and young people in the care planning process. It stresses that in order to make young people's involvement in the CPA '*a*

[12] The CAF is a shared assessment and planning framework for use across all children's services and all local authorities in England. It aims to help identify the young person's wider needs. The Care Programme Approach (CPA) is used by mental health services in England, in collaboration with social services departments, to put in place specified arrangements for the care and treatment of mentally ill people in the community. The CPA can be used across both child and adult settings by asking the question 'Has a CAF been undertaken?', which prompts practitioners drawing up the plan to link it back to the CAF (JCPMH 2012)

*reality rather than an aspiration',* careful attention needs to be paid to, for example, the design of paperwork so that service users do not feel excluded, and that communication systems need to be tailored to them.

**Box 6.4c**: Key features of transition audit and review procedures

| | Feature | Source |
|---|---|---|
| The transition review procedures | Monitor attendance at AMHS (DNAs or cancellations) | DH&DES (2006) |
| | Audit adherence to protocols | RQIA (2011) |
| | Involve young person in the **design and review** of services | NICE (2016)<br>NCB (2010)<br>DH&DES (2006)<br>SCIE (2011)<br>DH&DCSF(2008a; 2008b) |
| | Collect and use outcome- and service-level data and consider the use of targets and national quality criteria such as the 'You're welcome' criteria (see service environment section below) as a means of monitoring service performance. | SCIE (2011) |

Some policy documents also recommend the monitoring and review of attendance at AMHS to identify patterns of use (or drop out from services) after the transition to AMHS. As with all service developments and review, SCIE (2011) recommend the collection of outcome and service level data to monitor service performance. They recommend the use of target and national quality criteria as a means of monitoring service performance, suggesting You're Welcome criteria, as a means of reviewing how young people friendly the service is (see Box 6.4d below).

### *Young people friendly services*

Over the past decade there has been a growing awareness of the importance of the setting, culture and environment in which health and social services are provided to young people. For example, in 2011 the Department of Health in England published *'You're welcome': quality criteria for young people friendly health services*'. With a specific section on quality criteria for services for young people with mental illness, the You're Welcome quality criteria focus on 7 key themes including:

- accessibility (easy access via public transport; appointments outside college/work hours; can attend with or without carer; accessible for people with physical disability)
- publicity (what the service offers; how to access the service; what will happen when they access the service; how the service is linked to other services; how to access other services and get appropriate onward referral; how to make suggestions or complaints about the service; who else has access to any information that the young person shares with the service, and the circumstances under which information will be disclosed)

- confidentiality and consent
- the environment (care is delivered in a safe, suitable and young people friendly environment and young people are not asked, in public, any potentially sensitive questions that might be overheard in the reception or waiting area)
- staff training, skills, attitudes and values
- joined-up working
- monitoring and evaluation, and involvement of young people
- performance

**6.4d**: Features of a young people friendly service

| | Feature | Source |
|---|---|---|
| **The service environment** | A youth friendly environment:<br>welcoming décor, clear information, confidential, flexible appointments, policies, clear information, joined up working, staff training, involvement of young people in design and review of services,<br>monitoring, review and evaluation | DH&DES (2006)<br>DH (2003, 2011)<br>SCIE (2011)<br>Parker et al (2011) |

In 2009, the PHA developed a pilot programme of four 'One Stop Shop' drop-in services for children and young people providing information, education, sign-posting and, where appropriate, referral to specialist services. These services reflect many of the principles of young people friendly services described in the previous section and summarised in Table 6.4d. There are currently eight *One Stop Shops* supporting young people around a range of issues including mental health and wellbeing; suicide and self harm; sexual health; relationship issues; resilience; substance misuse; and coping with school/employment. (See Section 6.6.2 further information on different models of young people friendly services such as Headspace in Australia, YouthSpace in Birmingham and Jigsaw in Ireland).

### *6.4.3 Other considerations for transitions into adult mental health services*

#### *The needs of young people with ADHD/ASD, emerging personality disorder or eating disorders*

The Interfaculty Working Group (Lamb et al. 2008) also recommend that further collaboration and commissioning of services will be necessary to meet the gaps in the provision for young people with enduring neuropsychiatric disorders such as ADHD and ASD. In England, young people with ADHD are seen by CAMHS or paediatrics up to the age of 16 (or 18 if they remain in education). After 16 (or 18) their care route is unclear (Verity and Coates 2007). The recent NICE (2016) guidance on the transitions from children's to adult services comments

> *In many areas, CAMHS is designed to meet the needs of a wide range of disorders and problems such as attention deficit and hyperactivity disorder (ADHD) or autistic spectrum disorder (ASD), whereas AMHS tend to offer services only to those suffering severe and enduring illnesses such as psychosis or severe depression. The consequence of such different service provision is that young people in receipt of a service from CAMHS may find that, on reaching adulthood, their condition and presentation does not change, yet AMHS are not configured to support them.* (NICE 2016 pg 9)

Such gaps are described in the SCIE (2011) guidance, which highlights the specific support needs of young people with ADHD and ASD, as well as young people with emerging personality disorder.

> *Gaps in provision may include young people with attention-deficit hyperactivity disorder (ADHD), conduct disorder, autism spectrum disorders (ASD), emerging personality disorder, and those without a firm medical diagnosis.* (SCIE 2011 p.6)

The NICE (2013) guidelines on ADHD diagnosis and management, also make specific recommendations in relation to the transition from child to adult services, including: reassessment at school-leaving age to establish the need for continuing treatment into adulthood for all young people with ADHD receiving treatment and care from CAMHS or paediatric services; if treatment is deemed necessary, arrangements for a smooth transition to adult services should be made with details of the anticipated treatment and services that the young person will require (this process should usually be completed by the time the young person is 18); a formal meeting involving CAMHS and/or paediatric and adult psychiatric services should be considered during transition; the care programme approach should be used to aid the transfer between services, with the young person's involvement in the planning; post-transition to adult services, adult healthcare professionals should carry out a comprehensive assessment of the person with ADHD that includes personal, educational, occupational and social functioning, and assessment of any coexisting conditions.

The Bamford (2006) review also makes reference to the need to ensure young people with ASD are supported in the transition to adulthood.

> *A service is required specifically to assess children who are suspected to have ASD regardless of learning ability which can then provide follow up treatment, management, education and support and which will also support them in the transition to adulthood.* (Bamford 2006 p.55)

In addition, a report by the Royal College of Psychiatrists (2012) highlight the specific needs of young people with emerging personality disorder, who similar to young people with ADHD/ASD, are most likely fall to through the care gap during transition. The report draws attention to the findings from the NICE (2009) guidelines on the management of borderline personality disorder, which notes

> *Many young people who have been treated by CAMHS will not meet the referral criteria for adult mental health services, either because the services do not accept people with a personality disorder or because the service does not consider their difficulties to be severe enough to warrant intervention.*

The NICE (2009) guidance recommends that the transition to adult services should be planned and managed in lines with the DH&DfES (2006) *Good transition for young people* guidance. It also recommends that CAMHS and adult healthcare professionals should work collaboratively to minimise any potential negative effect of transferring young people from CAMHS to adult services. They should time the transfer to suit the young person, even if it takes place after they have reached the age of 18 years or continue treatment in CAMHS beyond 18 years if there is a realistic possibility that this may avoid the need for referral to adult mental health services (NICE 2009 pg 14). Review Question 2 describes the current evidence on young people with neuro-developmental disorders and eating disorders and service providers' views and experiences of the transition from CAMHS to AMHS.

### *Admissions to adult wards*

In the joint paper from the Interfaculty Working Group of the Child and Adolescent Faculty and the General and community of the Royal College of Psychiatrists (Lamb et al 2008), provide 'good practice' guidance on the provision of psychiatric services to adolescents and young people. As well as highlighting many of the elements described important for the transition into adult services (Box 6.4b above), the Interfaculty Working Group also recommend that pathways of care and treatment protocols are agreed between the local CAMHS and AMHS with respect to self-harm and emergency presentations to Accident and Emergency (A&E) departments. The Interfaculty Group call attention to English and Scottish policy documents which suggest 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 group recommends that if admissions are required in adult wards, such admissions should be for brief periods only.

Also of note is Recommendation 7 of the RQIA (2011) review, which recommends a cessation of the admission of young people to adult wards through the development of alternative community based services and interventions.

### *Transition and Recovery Oriented Care*

In recent years there has been a shift in focus on recovery oriented care, helping people in their recovery. The principles of recovery include the promotion of resilience, building and developing protective factors for children and young people. Within CAMHS this is supported by active intervention from the range of services designed to 'wrap around' the needs of the individual child/young person and their respective family (DHSSPS 2012).

The Implementing Recovery through Organisational Change (ImROC) Programme is a new approach initiated originally in England. ImROC aims to change how the NHS and its partners operate so that they can focus more on helping people experiencing mental illness with their recovery. The key aim of the process is to place person-centred recovery at the centre of organisational planning and delivery of these services. This model is based on local partnerships between statutory and non-statutory providers, service users and families so as to maximise the opportunities for service users to lead full and meaningful lives. It aims to improve communication and sharing of skills between stakeholders. ImROC is currently being implemented in a number of sites in adult services in Northern Ireland.

## 6.5 Review Findings: RQ2 What is needed?

The second review question explores the research literature examining the views and experiences of young people, their parents/carers, and service providers to answer the question 'What is needed during the transition from children and adolescent service to AMHS?' Four sub-questions frame this analysis.

a) How are transitions experienced by the young people?
b) Do young people with ASD/ADHD and eating disorders have particular needs during this process?
c) How are transitions experienced by parents/carers?
d) How are the transitions experienced by service providers?

This section of the review provides an overview of the research evidence from high quality systematic review level evidence, supplemented with findings of primary studies not included in the systematic reviews. Thirty one primary studies explored the views and experiences of young people, parents/carers and/or service providers. Eleven of the studies were conducted in the UK. Details of each of the included primary studies are presented in Appendix 9).

Ten studies (Burnham Riosa et al 2015; Backman et al In prep; Delman et al 2002; Jivanjee et al 2008; Klotnick et al 2014; Lindgren et al 2015; McGrandles and McMahon 2012, Swift et al 2013; Wheatley et al 2013; Dimitropoulos et al 2013) focused only on young people's experiences of services. Four studies focused only on parents/carers (Davis and Butler 2002; Gerten et al 2014; Jivanjee et al 2009; Woodward et al 2011), and twelve studies consulted

only with service providers (Belling et al. 2014; Davis et al 2006; Davis & Sondheimer 2005; Lindgren et al 2013; McNamara et al 2013; Richards and Vostanis 2004; Ahmed et al 2009; Hall et al 2013; Marcer et al 2008; Reale et al. 2014; Dimitropoulos et al 2012; Kaehne et al 2011). An additional twelve studies used case note reviews studies or secondary analysis to explore the transition from CAMHS to AMHS. One of the case reviews explored the transition of young people with eating disorder, six of the case note reviews and secondary analyses focused on young people with mental illness, and the remaining five studies focused on the transition of young people with ADHD. Details of each study are presented Appendix 9.

### *6.5.1 Views of young people*

Five of the systematic reviews (Paul et al 2014, Reale and Bonati 2015, Embrett et al 2015, Mulvale et al. 2016; NICE 2016) and two literature reviews (Ubido and Scott Samuel 2015, Davidson & Cappelli 2011) synthesised the research evidence on young people's experiences of transition to adult mental health services.

As described above, thirteen of the studies consulted with young people either alone (Burnham Riosa et al. 2015 (Canada); Delman et al 2002 (USA); Jivanjee et al 2008 (UK); Delman et al 2002(USA); Klotnick et al 2014 (USA); Lindgren et al. 2015 (Sweden); McGrandles and McMahon 2012 (UK); Wheatley et al 2013 (UK); Swift et al 2013 (UK) or in combination with parents/carers and/or service providers (Day et al 2007 (UK); Hovish et al 2012 (UK); Jivanjee & Kruzich 2011 (USA); RIQA 2011(UK).

All of the primary research with young people used qualitative methods employing either individual interviews (e.g. Burnham Riosa et al. 2015; Wheatley et al 2013; Swift et al 2013), focus groups (e.g. Delman & Jones 2002) or mixed methods of interviews combined with focus groups (e.g. Jivanjee & Kruzich 2011). A small number conducted case studies. For example Day (2007) undertook interviews with transitioning age young people, and with their parents, GPs and key-workers. Hovish et al (2012) used a similar methodology, whereby 11 young people were interviewed, with linked interviews with parents, CAMHS clinicians and AMHS clinicians.

The findings from each of the primary studies are synthesised and presented in a narrative summary. The messages emerging from these studies with young people are grouped in 6 themes:

- the need for preparation and formal transfer
- the need for a flexible transition
- perceived differences in care philosophies
- the importance of continuity of care and good relationships

- the wider support needs of young people
- changing role of parents/carers

### *Need for preparation and formal transfer*

The lack of formal transfer procedures has been identified as a barrier to good transitions in a number of studies (Richards and Vostanis, 2004; Singh et al 2010; Wheatley et al 2013). Research with young people has identified practical elements conducive to successful transition. These include: having at least one transition planning meeting, which was viewed as a key component in having a positive transition (Hovish et al., 2012; Wheatley et al 2013); and having planned meetings and treatment plans (Lindgren et al., 2014; Lindgren et al., 2015). Other activities identified as helping the process included, meeting the AMHS staff prior to transfer, being able to visit the service in advance of the transfer, and peer mentoring (Wheatley et al., 2013). Transfer meetings and parallel care were appreciated by the young people, parents/carers and service providers (Hovish et al 2012; Swift et al 2013). In general, the need for greater co-ordination emerged as an important part of the transition process (Dimitropoulos G et al 2013; Wheatley et al 2013).

### *The need for a flexible transition*

Different age boundaries between services have been proposed as a possible barrier to successful transition from CAMHS to AMHS (Murcott et al., 2014). For example, in some areas, adult services do not accept referrals for young people under the age of 18 years. Some CAMHS may only accept referrals for young people up to the age of 18 if they are accessing education. In their case study, McGrandles and McMahon (2012) describe how adopting a flexible approach to the transition of a young woman with eating disorder allowed her to transfer to adult services, but CAMHS continued to be involved with the 'formal' family therapeutic work. This case study also highlighted the importance of having a trusted member of staff to support the transition, as well as adopting a more flexible approach to meet the specific needs of the young person.

### *Meeting young people's developmental needs*

Reflecting the need for a planned transition process, research with young people has highlighted the importance of adult services which meet the developmental needs of the young person (Day 2007; Burnham Riosa et al., 2015; Jivanjee & Kruzich 2011; Gilmer et al 2012). Some young people are keen to transfer to services that reflect their developmental stage and specific needs. For some young people this might be a more adult-focused service (Burnham Riosa et al., 2015). For example, some of the young people in the study conducted by Day (2007) considered CAMHS to be child-like and not appropriate to their needs.

> *When I was 14 they had charts and things and were asking me to draw pictures and what my favourite colour is. They treat you like you don't know how to express yourself in words – they skirt around it.* (Day 2007 p.149)

This desire to move to a more adult oriented service also emerged in Burnham Riosa et al's study:

> *Krista viewed "starting over" as a welcomed opportunity. The symbolic nature of being "reborn" denoted her view of transition as a fresh start filled with "new responsibilities" with "new doors open." Sue viewed a program transition as a marker of her adult status: "I'm not being viewed as an adolescent anymore, I'm being viewed as an adult . . . and I look forward to it."* (Burnham Riosa et al 2015, p.462)

Some participants felt apprehensive about the move to AMHS, and described mixed feelings of anxiety and excitement in anticipation of moving to a new service (Wheatley et al., 2013; Day 2007). In Day's study, one young person described their fear of adult services:

> *very difficult the thought of going into adult [services], I feel slightly intimidated because I don't really understand it and also because there's some really unwell people in the CMHT (Community Mental Health Team) day service and I feel a bit frightened'* (Day 2007 p.149)

A number of studies uncovered the perception that adult services were not equipped to deal with young adults (Richards and Vostanis, 2004, Swift et al 2013). Parents and young people consulted by Gilmer et al (2012) identified the importance of improved scheduling of services, more efficient and convenient ways of travelling to sessions, and more housing/employment support for youths at a transitional age.

### *Perceived differences in care philosophies*

Some of the research with young people identified their perception of differences in the care philosophy of the two services. The flexible approach adopted by many CAMHS services was perceived to be in sharp contrast to a more clinical driven and individualist approach adopted by AMHS (Day 2007, Swift et al., 2013; Burnham Riosa et al., 2015). One study (Swift et al., 2013) found some of the young people with ADHD perceived adult services as employing a more individualist approach requiring more autonomy from the young person. The transition process was perceived to be the responsibility of the professional, with little preparation involved, which resulted in some participants feeling concerned as to how their needs would be met. Interestingly, Klotnick et al., (2014) found that whilst young people who had transitioned to adult services provided lengthy descriptions of the CAMHS services and their

relationships with the clinician, their descriptions of the adult services were vague and superficial.

The difference in the care philosophies and treatment approaches is highlighted by Bruce and Evans (2008) who provide an example of how a young person may be receiving individual and family therapies in CAMHS, but when transferred to adult services access to non-pharmacological services and psycho-therapies is much more limited. They also describe the absence of a common language, whereby CAMHS describe the different tiers that form the structure of their service, and how AMHS use adult terms such as standard and enhanced CPA. They recommend more joint working, with liaison models with specialist workers working astride of the two services, the use of clear protocols and guidelines for transitions, as well as joint training as a means to breaking down the barriers between the two services.

### *The importance of continuity of care and good relationships*

Related to the care philosophy, the qualities and characteristics of the clinician were pivotal to a positive care and transition experience (Swift et al 2013). Qualities associated with engagement with the service were 'understanding', 'supportive and informative' and 'non-judgemental'. The importance of a gradual transition, with support from the keyworker and or parent/carer was highlighted in the Track study (Hovish et al 2012). Continuity of therapeutic relationships with keyworkers contributed to the young people feeling prepared and supported before, during and after the transition (Hovish et al 2012; Swift et al 2013).

### *The wider support needs of young people*

The transition from CAMHS to AMHS coincides with many other social and educational transitions. Hovish et al (2012) found that many of the young people moved out of the family home during the transition period, with supported accommodation being the destination for over half of the sample. A strong theme in the Hovish et al study was the impact of other changes happening in parallel with their transition to AMHS, which meant some young people had to negotiate complex multiagency contacts with parallel involvement of services such as social services, homeless organisations, and counselling services. Some young people were also transitioning to other adult medical services e.g. asthma, diabetes. Such needs highlight the importance of either a generic young people's service and / or a transition co-ordinator to help young people navigate the different services.

### Changing role of parents/carers

Concerns about confidentiality may prevent some adult services from involving the parent/carer of the young person, unless the young person gives clear consent for this (Bruce & Evans 2008). Feelings of anxiety and uncertainty about adult services were prevalent in some studies (Lindgren et al., 2014; Swift et al., 2013). Further, some felt unsafe and

neglected after transferring to AMHS (Lindgren et al., 2015). Whilst some young people looked forward to greater responsibility, some young people were concerned about the prospect of having to make decisions autonomously (Lindgren et al., 2014; Lindgren et al., 2015; Swift et al., 2013).

Given the reduced executive functioning of young people with ADHD, parents and carers were found to have an important role in their care (Swift et al., 2013), with young people often highly reliant on them for support to attend appointments and / or to take medication. The need for parents/carer continued support during and after the transition was openly accepted and thought to be required by the majority of young people with ADHD during transition.

**Box 6.5** - Summary of key themes emerging from the research with young people

- The need for further preparation for young person and family/carer (particularly for young people with ADHD)
- More consistent and seamless service with involvement of parent/carer (where relevant)
- Opportunities to be introduced to the adult service e.g. meeting, photo of new clinician
- Visit to adult service in advance of transfer to overcome fears and concerns about the service
- One clinician (consistency of service provider) in new service to help establish new relationship, and sufficient time during appointments to establish rapport and build relationship with adult service staff
- Flexibility to transition when young person is ready (earlier or later)
- Good transition to primary care if not accepted to AMHS (particularly YP with ADHD or ASD)

### *6.5.2 Views of parents/carers*

A total of seven studies involved some level of consultation with parents. Five of the studies consulted with parents alongside young people and/or professionals (Jivanjee & Kruzich, 2011, Davis and Bulter 2002; Hovish et al 2012; Gilmer, Ojeda, Leich et al 2012: RIQA 2011). Four studies focused only on parents/carers (Davis and Butler, 2002 (USA); Gerten et al 2014 (USA); Jivanjee et al 2009 (USA); Woodward et al 2011(USA)). Whilst most studies used self-completion surveys to consult with parents (Davis and Bulter 2002; Gerten et al 2014; Woodward 2011; RIQA 2011), a small number of studies used semi-structured interviews (Hovish et al 2012; Day 2007) or focus groups (Jivanjee et al 2009). Overall, the consultations with parents involved small sample sizes ranging from 6 parents in the case studies (Hovish et al 2012; Day 2007) to 115 parents in the self-completion survey (Wheatley et al 2013).

#### *Preparation and planned transitions*

The Track study found that just over half (54%) of young people had attended at least one transition planning meeting. Parents/carers of young people who had not attended transition meetings felt this would have been helpful (Singh et al 2010).

The need for more preparation and collaborative planning was identified by parents/carers in a number of studies (Davis and Butler 2002, Jivanjee, Kruzich, and Gordon 2009). Parents in one study (Woodward et al., 2011) highlighted the need for transition programmes to become more person centred, to assess the young person's health characteristics and service needs.

### *The need for a flexible service*

The need for a flexible service expressed by young people is echoed in the research with parents/carers. In a focus group study with young people and parents (Jivanjee & Kruzich, 2011), parents highlighted the difficulties caused by restrictive eligibility criteria and the loss of services after age 18 years. Similarly, Davis and Bulter (2002) found parents to be unhappy with the transition process, with only a small number of parents reporting helpful transition services.

### *Information needs*

Parents and carers expressed a need for more information, including information about the transition process (Davis & Butler 2002), and their child's condition (Gerten et al. 2014).

### *Responding to young people's developmental needs*

Similar to the views of the young people described above, in the research with parents the need for developmental appropriate services that addressed young people's broader needs such as housing and employment was a recurrent theme (Jivanjee & Kruzich 2011; Davis & Butler 2002; Gerten et al 2014; Gilmer, Ojeda, Leich et al 2012).

A small number of studies identified parents' concerns about the stigma associated with adult services which act as a barrier to young people from availing of the services (Davis and Butler 2002).

### *Continued parental involvement*

As discussed above, for many young people the transition to adult services means the reduced involvement of parents/carers in their care. Only a minority of parents in the Track study reported involvement in care after the transition, and many described having difficulty adjusting to their reduced involvement. Parents wanted more involvement and more flexibility in the timing of the transition (Hovish et al 2012). Some young people with mental illness require significant support from their parents/carers families beyond adolescence, but some families find it extremely challenging to provide this continued support (Jivanjee et al. 2009).

As young people reach legal adulthood, parents may no longer feel they are as responsible for the well-being of their children (Jivanjee et al. 2009). Parents of older young people with serious mental illness can experience increased conflict and strained relationships (Haber et al 2015).

Nonetheless, a number of studies have highlighted the importance of continued parental involvement and support. For example, Gerten and Hensley (2014) emphasise the important role parents/carers play as advocates, coordinators of care, 'medication managers', as well as being a nurturer during the transition. As discussed previously, for young people with ADHD and ASD, the importance of continued parental support was a recurrent theme (Swift et al 2013).

| **Box 6.6 - Summary of key themes emerging from the research with parents/carers** |
|---|
| • The need for preparation for young person and family/carer<br>• More collaborative approaches<br>• The importance of positive relationships with service providers<br>• Greater flexibility to respond to the specific needs of the young person (i.e. no rigid boundaries)<br>• More community based services and services that address the wider support needs of young people<br>• Services in young people friendly settings to reduce stigma<br>• Support with housing, education/training etc.<br>• More information about the services and the young person's condition<br>• Continued parental involvement in adult service (particularly for young people with ADHD)<br>• As an advocate for the young person<br>• To support treatment and encourage ongoing attendance at services |

### *6.5.3 Views of service providers*

Seven studies had a specific focus on service providers' and professionals' views on and experiences of the transition process (Belling et al. 2014 (UK); Davis et al 2006 (USA); Davis & Sondheimer, 2005 (USA); Lindgren et al 2013 (Sweden); McNamara et al 2013 (Ireland); Richards and Vostanis 2004 (UK); Reale et al. 2014 (Italy); Dimitropoulos et al 2012 (Canada); Kaehne et al 2011) An additional 3 studies had a particular focus on service providers' views on the needs of young people with ADHD (Hall et al 2013 (UK); Marcer et al 2008 (UK); Reale et al 2014 (Italy). Only one study examined service providers' views on the transition needs of young people with learning disability (Kaehne, 2011 (UK), and one explored clinicians' perspectives of the transition support needs of young people with eating disorders (Dimitropoulos et al., 2012 (Canada). None of the located studies explored service providers' views on the support needs of young people with ASD.

#### *Flexibility to respond to young people's developmental needs*

Reflecting the findings from the research with young people and parents, a recurrent theme in the research with service providers is the importance of flexibility in the service to respond to the developmental stage of the young person. This might mean allowing the young person to transition to adult services at a younger age, or conversely remaining with youth services until

the young person is prepared to make the transition. Sukhera et al (2011) highlight the disparity between the needs of the young person, and the needs of the institution:

> *Institutions tend to emphasize bureaucratic and legal transitions with boundaries focused on age or diagnostic criteria while real-world developmental transitions involve maturation, increased competence and social changes.* (Sukhera et al 2015, p. 273)

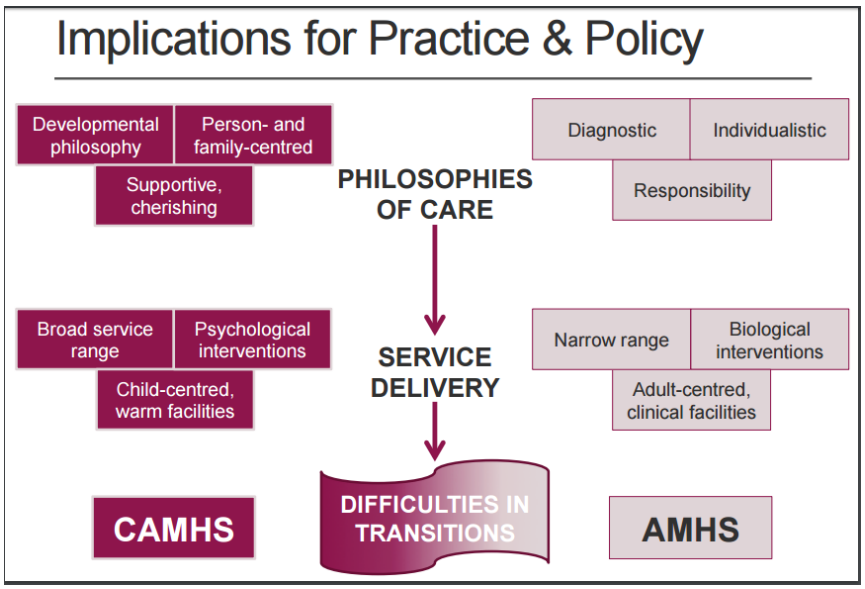
Some authors suggest that a gradual rather than an abrupt change might help the process. (Arcelus et al 2008; Hovish et al 2012). A number of service providers acknowledged that adult services were not always equipped to meet the multifaceted needs of young adults (Richards and Vostanis, 2004; Belling et al 2014).

### *Different care philosophies*

Perceived differences in the care philosophies is a recurrent theme in the primary research. Mulvale et al's (2016) review of care philosophies found distinct philosophical differences between CAMHS and AMHS with respect '*to how the challenges facing young people are understood, the importance of family and social context, and where the balance lies in the need to protect versus expect responsibility of youth'*.

Within the literature the CAMHS model is generally viewed as embracing a developmental perspective, and adopting person-centred and supportive approach to care. AMHS was viewed as adopting a more medical model, with expertise in diagnosis and adopting an individualist approach, whereby a higher level of autonomy is expected. Randall et al summarise the differences between the two models of care in Figure 6.1 below.

Figure 6.1: Summary of the care philosophies of the two systems




Source: Randall et al (2016)

A number of studies (McLaren et al., 2013; Lindgren et al 2013; Belling et al 2014) found different care philosophies, with service providers' lack of understanding of the respective service's culture, acting as a major barrier to successful transition. This barrier is exacerbated by a lack of successful communication or transfer of information. More collaborative working, involving joint posts and parallel working between the two services have been suggested as a means to diffuse negative beliefs and improve understanding.

McLaren et al. (2013) highlight the importance of shared education and training, standardised approaches to record keeping and information transfer, and management strategies in breaking down the mutual misperceptions, differences in attitudes and beliefs that can exist between services.

Singh et al (2014) stress the need to break down the practical differences in referral criteria for AMHS (with its traditional focus on patients with severe and enduring mental illness), and consider this as a priority action to be tackled by commissioners and policy-makers as well as service provider organisations, whether statutory or voluntary.

### *Continuity of care*

Continuity of care has been examined in detail in the UK ECHO study which explored the barriers to and facilitators for good continuity of care among people with long term psychotic disorders (Burns et al 2007). Barriers to good continuity of care included poor communication (underpinned by a 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 reorganisation (Burns et al, 2007; Belling et al 2014).

Staff consulted in the Track study (Belling et al 2014) perceived adult services as not meeting the needs of young people with neuro-developmental disorders, and young people with complex needs, and highlighted the need for the development of AMHS staff skills and confidence to provide support to such young people.

Lindgren and colleagues (2013) in their research with CAMHS and AMHS professionals found experiencing discontinuity in the therapeutic relationship (between the young person and CAMHS professional) was a major factor for young people's disengagement from adult services at the point of transfer. Suggestions for improving continuity of care included the use of case workers and joint working (Hovish et al 2012). Although, one keyworker in the Hovish et al study raised concerns about parallel care on the grounds of clinical governance.

In the recent ITRACK study, McNamara et al. (2013) found that just over half of CAMHS (58%) and AMHS (57%) consultants never identified a member of AMHS to welcome and support the YP in AMHS.

### *Information sharing*

In their 2004 study, Richards and Vostanis reported that communication between CAMHS and AMHS was variable, with no formal transition. Similar findings were noted in a Swedish study (Lindgren et al 2013) and in the ITRACK study (McNamara et al 2013). Lindgren et al., (2014) found poor information transfer and shortcomings in communication between the two services had a negative impact on continuity of care. In their survey of CAMHS and AMHS consultants, McNamara et al (2013) found that there was a lack of standardised procedures during the transition period, and that while information exchange of paper case notes was described by most, joint working was limited.

Similar to Lindgren et al, in their study of mental health professionals and representatives from voluntary sector organisations, McLaren et al. (2013) identified the barriers to good information transfer included different electronic record keeping systems and the lack of mutual understanding of each other's' services. Recommendations to improve transitions included the use of strategies such as early communication, allowing more time for the young person and their families to adjust to changes in services, and information sharing by all concerned in transition.

Perceived differences in funding, described by Davis (2003) as 'funding jealously' was identified to be a barrier to collaborative work between paediatric and adult services in Canada. Related to 'funding jealous', silo working has been identified in a number of papers as a barrier to collaborative working (Davidson & Cappelli 2011; SCIE 2011).

In their exploration of the organisational factors that impede or facilitate transition between the two services, Belling et al. (2014) found a mutual lack of understanding of the services, together with restricted eligibility criteria due to the perceived lack of resources can impact on the transition from CAMHS to AMHS, resulting in a disruption in continuity of care of young people.

### *Involvement of parents*

As discussed above, the involvement of parents in the transition and in adult services is dependent on the consent of the young person. Service providers describe different levels of involvement of parents in the transition process. For example, in the ITRACK study (McNamara et al 2013), nearly all (89%) of the CAMHS consultants reported always involving parents in the care plan, compared to just over half (52%) of AMHS consultants.

For some young people, the transition period with emerging adulthood can result in tensions between wanting to become independent and to be treated as an adult, and the need for practical support during the move into adult services. Lindgren et al. (2013) suggest that some young people may prefer not to continue to have family involvement following the transition to adult services and in these cases there may be little or no impact on transitions. In contrast, young people who had been well-supported by family in CAMHS may find it difficult to make a decision about including them in their care, and may feel less supported to make the transition and thus less likely to continue in AMHS.

Some authors (Davidson and Cappelli 2011) argue for the need to encourage the inclusion of parents and carers while at the same time balancing and fostering a sense of independence and responsibility in young people.

### *Specific needs of young people with ADHD or ASD*

A small number of studies explored service providers' views on the needs of young people with ADHD (Hall et al 2013 (UK); Marcer et al 2008 (UK); Reale et al 2014 (Italy). These findings are integrated within Section 6.5.6, below.

**Box 6.7 Summary of key themes emerging from the research with service providers**

- Perceived limited resources in AMHS can result restrictive eligibility criteria with focus on young people with severe and enduring mental illness
- Adult services not always equipped to meet the multifaceted needs of young people transitioning from CAMHS to AMHS
- The two services were viewed by many as having different care philosophies, with CAMHS adopting a more holistic and person centred approach, and AMHS offering a more medical model expecting a higher level of autonomy
- Reflecting the different care models, some service providers had a limited understanding of each other's service (due in part to limited collaboration and joint working)
- More flexible services to respond to developmental stage with a more gradual rather than abrupt change
- AMHS staff perceived less equipped to deal with young people with learning disability/ADHD/ASD
- Poor communication between services resulted in poor continuity of care for the young person
- Different information systems
- Lack of standardised procedures

***Recommendations for improvements***

- More planning and preparation including early communication with services, young people and parents
- More collaborative approaches including joint working and use of case workers
- Greater flexibility to respond to the specific needs of the young person (i.e. no rigid boundaries)
- Provide AMHS staff with skills and confidence to support young people with ADHD/ASD

### *6.5.4 Case note reviews and secondary analysis*

Three papers from the Track study (Paul et al 2013; Singh et al 2010; Islam et al., 2015) report on case review analyses documenting the transition pathway of young people leaving CAMHS. The first stage involved a retrospective analysis of all young people (n=154) cases reaching the upper age boundary in 6 CAMHS in England (Paul et al 2013; Singh et al 2010). Of the cases analysed, 131 (85%) were thought to be suitable by CAMHS clinicians for transfer to adult services, 102 were referred and 90 (89%) were accepted by AMHS. The main reasons for non-referral to AMHS were: refusal of the young person or parents/carers (9%) to proceed with the referral; CAMHS clinicians perceiving that AMHS would not accept the referral or that that AMHS had no appropriate service (9%) or that CAMHS were still planning to refer to AMHS (4%).The Track Study identified 4 elements of optimal transition (described in Chapter 4). Of the 90 cases accepted by AMHS, the element of optimal transition most often met was continuity of care (70%), followed by at least one transition meeting (40%), good information transfer (24%). Only 4 cases met all four elements of optimal transition.

In a second paper, Islam et al (2015) focused on the 64 cases from the Track study (34% of cohort) who despite having ongoing mental health needs, had not been referred to AMHS on reaching the transition boundary. Nearly half (48%) of these cases had emotional/neurotic disorders, and a quarter (23%) had neuro-developmental disorders, highlighting that young people with these disorders are those most likely to fail to access secondary healthcare. Over half (56%) of the young people were discharged to the GP, a quarter (25%) remained in CAMHS. It was unclear whether the GPs have sufficient training or expertise to manage or deliver mental healthcare to young adults presenting in this way. Over half of those who did not transfer to AMHS continued to receive some CAMHS care after crossing the transition boundary, which may have had implications for the capacity of CAMHS to respond to new referrals. Singh et al (2010) found different working cultures, lack of clarity on service availability and eligibility issues can also influence CAMHS decisions to refer the young person to AMHS. Islam et al note that it is important for CAMHS to refer young people to adult services to document the need for provision and better commissioning for these young adults. Retaining cases in CAMHS also risks young adults disengaging from services that are not age appropriate as well as reducing the capacity of CAMHS to respond to new referrals.

Case review analyses have also been used to examine the transition among young people with ADHD (Ogundele 2013, Taylor et al 2013; McCarthy et al 2013) (see section 6.5.5 below). No case review studies that examined the transition pathways of young people with ASD were located. Although, Colver and colleagues 2013 are currently undertaking a longitudinal study of the transition of young people with complex conditions, including young people with ASD (Colver et al. 2013).

### *6.5.5 Research with specific groups of young people*

#### *Young people with ADHD*

Over the past 20 years, services for children with ADHD have been well developed, but recent research and policy identifies gaps in service provision for young people aged over 18 with ADHD (Healthcare Improvement Scotland, 2012, Royal College of Psychiatrists 2013). Approximately half of young people with ADHD in adolescence will require continuing care (Coghill et al., 2008). There is also an increasing number of adults whose ADHD has not yet been identified or who have been misdiagnosed (Nutt et al.,2007). As discussed above, diagnoses of ADHD and ASD often do not meet the criteria for referral to adult mental health services, and thus leave some young people's needs unmet following discharge from CAMHS (Munoz-Solomando et al., 2010).

Four UK studies have consulted either with young people (Swift et al 2013) or clinicians (Hall et al 2013, Marcer et al 2008, Hall et al 2015) to explore the specific needs of young people

with ADHD. Such studies have noted the lack of structured guidelines, care pathways and the limited communication between children's and adults' services as major barriers (Hall et al 2013, Hall et al 2015). Other studies (Hall et al., 2013) found AMHS clinicians often feel ill-prepared to deal with ADHD, some lacking in confidence and experience in dealing with clients with ADHD. Marcer et al identified the need for a specialised ADHD adult service. A finding echoed in an Italian study (Reale et al., 2014) which found that after discharge from paediatrics, the majority (70%) of young people were monitored by a GP. Of the young people who continued to use mental health services, the majority were monitored by the paediatric service.

The case review analyses of the TRACK study (Singh et al 2010, 2013) (described above) identified young people with neuro-developmental or emerging personality disorders as most likely to fall through the CAMHS-AMHS gap. This is confirmed by two other case review studies (Ogundele 2013, Taylor et al 2010). In his case review of 102 young people with ADHD eligible for transition in Liverpool, Ogundele found that nearly three quarters (73%) of patients attending paediatric mental health services for ADHD are lost in the transition to adult services (Ogundele 2013). Similarly, in their review of 139 cases in Sheffield, Taylor et al (2010) found that at transition many young people with ADHD often have ongoing symptoms and co-morbid conditions. Swift et al (2013) found that transitions were more difficult for young people when ADHD was the main or sole clinical problem. Even though there is a clear and recognised need for continued care for young people with ADHD, the loss to follow-up is in part due to poor understanding the disorders (Marcer et al 2008).

One of the challenges for adult care of ADHD is the ongoing debate on the young adults' use of ADHD drugs which are licensed only for children (Nutt et al, 2007). The uncertainty in the current prescribing for young adults with ADHD, may explain the findings from McCarthy et al's (2009) longitudinal cohort analysis which found a discontinuation of prescribing in older adolescents and young adults, with no patient receiving treatment by age of 21.

A large scale UK national study, the Catch-US study (Ford et al 2016), is currently underway to track the experiences of young people with ADHD as they transition out of children's services. This study will examine how many young people are in need of services for ADHD as adults, and will explore how current service users and service providers experience this transition.

### *Young people with ASD*

Kaehne et al (2011) identify transitions from education into training, employment, day services, and independent living is a time of significant worry, stress and anxiety for young people with disabilities, particularly those with ASD. They note at this time of need, access to mental health

services can be difficult given the stricter eligibility criteria for AMHS (Kaehne, 2011). Where a young person is ineligible for adult mental health support, CAMHS may make a referral to adult social care, but their strict eligibility criteria could similarly mean that a young person is not eligible for support.

In their scoping review to identify successful models of transitional care for young people with chronic health conditions, Watson et al (2011) did not identify any published models to support young people with ASD transition to adult mental health services, highlighting the *urgent need for further service developments for this common neuro-developmental disorder.*

Our review identified only one primary study focused on the needs of young people with ASD as they transition from CAMHS to AMHS, a US based study by Cheak-Zamora et al., (2013). One of the barriers identified by clinicians to preparing young people for the transition into adult life was the short appointment times, which meant the most immediate needs being prioritised. Similar to the UK studies on adult service providers' knowledge of ADHD ((Hall et al 2013, Marcer et al 2008), Cheak-Zamora et al's study also identified adult providers' limited understanding of this neuro-development disorders as a major barrier to good transitions.

A study undertaken by the National Autistic Society (Madders et al 2010) found that most CAMHS teams 'did not routinely plan for transition to adult services', and lacked any kind of formal protocol for dealing with transition. Those who did take steps for a smooth transition to adulthood often found it very hard to get adult mental health services to buy into the process, as they would not plan support for anyone who was not presently eligible for their service' (p.20).

### *Young people with eating disorders*

One review, Winston et al (2012) provides an overview of the literature on the transition from CAMHS to AMHS for young people with anorexia nervosa. Their search strategy identified only 2 UK papers (Arcelus et al 2008; Treasure et al 2005) with a focus on the needs of young people with eating disorders. From the available international literature, Winston et al describe some of the differences in the approach to treatment offered by the two services, whereby CAMHS tend to offer more family focused therapy and encourage the young person to externalise the illness. Adult services are more likely to adopt individual therapy. In CAMHS, parents are often involved in managing the young person's eating, and helping bring about change. In adult services, the shift is towards the young person taking control over their eating and developing a sense of autonomy. Thus, for the young person making the transition from CAMHS to AMHS, the experience can be difficult and for some *'bewildering'*. Winston et al cite one UK opinion paper (Treasure et al 2005) which describes the transition to be poorly defined, with a lack of clear procedures for managing the process.

Our review identified 3 primary studies focused on the needs of young people with eating disorders as they transition from children's services to adult services.

In a Canadian study, Dimitropoulous et al (2014) conducted interviews with 15 young people as they made the transition from children's eating disorder service to adult eating disorder service. Young people advocated for better coordination and communication between child and adult mental health providers. They also described the importance of adult providers increasing their knowledge about eating disorders, and the importance of balancing the young person's need for independence versus ongoing service involvement in supporting behavioural change. Recommendations to improve the transfer of care included focusing on developmental stage rather than age to determine readiness for transition; and discussing the options for 'adult treatment' prior to transfer. Similar to other research the young people with eating disorders felt that children's services should provide young people with opportunities to develop practical skills to manage their care independently. In a separate study, Dimitropoulous et al (2011) also examined clinician's perspectives of the transition needs of young people with eating disorders. The clinical factors associated with eating disorders were viewed to interfere with a successful transition. For some young people, the denial of the condition was viewed to impact on the willingness to engage in treatment, and acted as a barrier to preparing for adult services. For some young people the illness can affect normal developmental process which is also a consideration for the transition to adult services, and the continued need to involve parent/carers.

Using a case note review study of all young people referred to a specialist adult eating disorder clinic, Arcelus et al (2008) compared young adults referred to a specialist Adult Eating Disorder Service (AEDS) who had previous experience with CAMHS, with those who did not have previous experience of CAMHS. The study found a high percentage of young people were referred to the adult service by GPs, which suggested a lack of seamless care pathway between children's services and adult services.

### *Young people in care*

Two of the located reviews included a focus on young people in care. Young people in care have increased risk of poor mental health (Tarren-Sweeney 2008). Akister et al (2010) explored the research evidence on mental health outcomes of young people transitioning into adulthood, and argue that more retrospective and longitudinal research is required to identify the factors and systems that promote successful health and wellbeing outcomes for care leavers.

Whilst the Akister et al review did not focus specifically on transition from CAMHS to AMHS, it covered some relevant background literature including the risk factors associated with poor

mental health outcomes. Akister et al cite research by Dixon and colleagues (Dixon et al 2006; Dixon 2008) which describes some of the factors associated with positive transitions out of care, including good preparation for leaving care (especially among older young people). A strong friendship network, good life skills and social skills appeared to be important in promoting positive wellbeing (Dixon 2008). The review also describes some of the predictors of poor mental health; including older age on entry into care, intellectual disability, placement instability, and adverse life events. Leaving care early, poor housing and social isolation were found to be associated with poorer outcomes. A number of researchers (Akister et al. 2011; Lopez and Allen 2007; Christian and Schwarz 2011) describe the transition to independent living for care leavers as extremely challenging as they tend to have to face transition to adulthood earlier than young people not in the care system, and when they do they have fewer resources to draw on, poorer finances, limited professional support, and few personal adult resources. Such difficulties, combined with poor transition processes, increase the risk of poor health and wellbeing outcomes, as described by Christian and Schwarz (2013):

> *'Many of the barriers to transition to adult care that exist for the general population also jeopardize the transition for maltreated children, including the lack of shared planning among paediatric and adult systems, loss of case management'* (Christian and Schwarz 2013 pg 141)

More stringent admission criteria in adult mental health services also affects the care leaver's ability to continue to access the services as they transition into adulthood.

Christian and Schwarz's review highlights the paucity of health care models that meet the needs of young people transitioning out of state care. They describe changes in the legal system in the US, whereby child welfare agencies are required to make new efforts for the planning of the transition to independent living, and to provide ongoing foster care support for young people aged 18-21 who remain in school or who are employed. They call for greater sharing of successful medical and mental health transitions, and for more collaboration with youth justice, education and child-welfare to provide the support and direction to young care leavers.

### *Young people transitioning from secure care*

Young people within inpatient CAMHS often experience more complex, severe or persistent mental health problems (McDougall et al., 2008). Transitioning into an inpatient or community adult service, can be a frightening prospect for some young people and can be particularly challenging, as they undergo many they transitions in their living environment, their peer groups, as well as their service (Singh et al., 2010). Our review located only one study (Wheatley et al., 2013) exploring young people's experiences of the transition from secure

settings. This UK based study explored 8 young women's experiences of the transition from (moderate to high secure) CAMHS inpatient services to AMHS. Similar to other studies, observing aggressive behaviour of other patients was cause of concern for the young women. Factors such positive relationships with staff and other patients, and the need for informed involvement were identified as important in the transition process. An increase in positive statements regarding the post-transition experience suggests that the transition had been positive for some, although this might be explained by their transfer to lower security and community services. The study highlighted the importance of moving beyond procedural issues of transition and focusing on the social and culture gaps that appear to divide CAMHS and AMHS.

## 6.6 Review Findings: RQ3 – What works?

### *6.6.1 Findings from the systematic reviews*

The systematic reviews included details on 6 approaches (2 from the USA, 1 from Canada, 1 from Australia, 1 from England). An additional 3 studies describing pilot initiatives in England were identified from the searches. The quality of the evaluations varied. None employed randomised control trials, but one study (Gilmer et al 2012) utilised a quasi-experimental design using a control group with similar profile of young people attending a standard adult services. None of the remaining studies employed control groups for comparison. The majority of the studies were directed at young people with mental health problems. One paper (Verity and Coates 2007) describes a pilot study of a specialist service for young people with ADHD. None of the studies explored transitional models specifically for young people with ASD or eating disorders.

The previous section presented a summary of the barriers to and facilitators for good transitions as experienced by young people, their parents/carers and professionals. In response to some of the barriers to good transition, Singh et al (2005) suggest 5 approaches that might be considered as a means to improve the transition experience:

1. the use of protocols and guidelines to managing the interface;
2. specialist services for young people aged 14-25 (including early intervention services);
3. liaison models whereby child and adult psychiatrists routinely attend meetings to discuss cases (drawing on examples where the two service providers meet to discuss children of parents who have mental illness);
4. joint working whereby children's service bring their knowledge and *understanding of developmental processes in the assessment and management of young people*, and where *adult services are better equipped to provide the diagnostics precision and appropriate pharmacological treatments* (Singh et al p.294);

5. specialist services provided by staff who are members of both children and adult services (e.g. transition co-ordinator).

Singh et al also suggest training programmes for specialist workers to work with young people aged 14 onwards. Since the publication of the Singh et al (2005) paper a number of models have been described in the literature. In the section below we present the available evidence of the effectiveness of models which have used some of the above strategies. Seven of the reviews included a focus on the effectiveness of different models transition age services (Paul et al 2015, Sukhera et al 2015; Davidson & Cappelli 2011; Embrett et al 2015; Reale and Bonati 2015; DiReeze et al 2015; NICE 2016). From the papers identified in the reviews, and from additional searches, a total of 12 papers describing 6 models of transitional care were identified.

Of the 19 papers included in the Paul et al.(2014), only three described interventions or models of care for improving transitional care (see below for more detail). All three were initiatives from USA. One examined the effectiveness of a case management model (Styron et al 2006), one evaluated a transition support model (Haber et al 2008), and the third, an outpatient transition programme (Gilmer et al 2012). Although all three programmes were described as improving clinical and social outcomes for those with facilitated transition, none of the studies employed robust methods such as randomised control trials (RCT), and each model was deeply rooted within its own particular and specific healthcare context.

The NICE (2016) review also only identified one intervention (Gilmer et al 2012) aimed at improving transitions for young people transitioning to AMHS. Ubido and Scott Samuel (2012) included summaries of 4 published evaluations of interventions, and described 4 examples of practice in the UK. In their exhaustive review of the literature Reale and Bonati (2015) identified 33 studies exploring the transition from children's to adults' services, of which 2 described either a protocol (Hall et al 2013) for transitions to adult service or a transition service (Gilmer et al 2012).

Whilst not providing details of individual study, in their narrative review of mental health service delivery for transition aged youth, Sukhera et al (2015) identified four main elements for more effective transitions.

- *Coordinated and continuous systems of care*. This includes continuity of care across and between organisations. They cite Davis, Koroloff & Johnsen's (2012) work on improving organisational relationships and systemic integration to improve relationships between organisations in the transition network.

- *Flexible organisations that align developmental and institutional transitions*. They argue that the disparity between patient and institutional needs can result in poor transitions. Young people with mental health problems or developmental delays can be less prepared for organisational transitions. Sukhera et al argue that rigid adherence to institutional priorities can have negative consequences on young people and families. Institutional flexibility is an important component for developmentally appropriate health care, *'A gradual rather than an abrupt change, carefully managing transition across and between services with simultaneous developmental and psychosocial transitions, and avoiding transitions during a crisis or acute episode of care'* (Sukhera et al pg 273).
- *Youth and Community-Centred Programmes.* These are programmes that respond to some of the barriers to accessing services (e.g. concerns about confidentiality, stigma associated with services). Youth involvement in the design and review of services (Munoz-Solomando et al 2010).

### *6.6.2 Findings from the primary studies*

The review uncovered 12 papers describing nine models of services which addressed one or more of the features described above. The quality of the studies varied from descriptions of services to longitudinal evaluations. Weakness in studies included lack of control or comparison group, small sample sizes, limited detail on recruitment procedures, and different outcome measures.

The available evidence is grouped into four categories:

1. Use of protocols;
2. Managed transition services;
3. Youth and community centred programmes; and
4. Mental health services for 14-25 year olds

#### *Use of protocols*

Protocols serve as important basis for service improvement. The lack of consistent protocols for transition remains a significant barrier to effective practice (RCPMH 2012). Studies exploring the use of protocols in the transition into AMHS has identified great variation in the level of detail on operational procedures involved in transitions: some protocols make very specific and clear recommendations on what clinicians should be doing; others make only

general statements, such as advising adherence to the Care Programme Approach (CPA) guidelines (Singh et al 2008; Singh et al 2010; McGrath 2010 cited by JCPMH 2012).

The JCPMH (2012) describe 4 points of good practice in the protocols to support transitions. These include:

- promote person-centred planning;
- enable continuity of care;
- offer flexibility in decision-making; and
- have sufficient detail in the operational procedures to ensure efficacy and consistency.

Two UK studies (Singh et al 2008; McGrath et al 2010) explored the use of protocols for the transition from CAMHS to AMHS. The TRACK study (Singh et al 2008; Singh et al 2010) explored the factors that may facilitate or impede transitions from CAMHS to AMHS in Greater London. Forty two of the 65 teams contacted responded to the survey, from which 13 transition protocols were in operation. This study found that protocol-sharing units varied greatly. Most protocols referred to the National Service Framework (NSF) documents (Department of Health 2003; Department of Health and Department for Education and Skills, 2004), but not all met the requirements of the NSF. Although the protocols identified the centrality of the service users' involvement in the transition process, none had specified how service users should be prepared for the transition. It was also unclear what systems were in place to meet the ongoing care needs for young people not accepted by AMHS, thus potentially creating gaps in the continuity of their care. Three quarters had not provision for follow-through if the young person was not referred to AMHS.

In her scoping study of transition activity and models of good practice across the East Midlands Region, McGrath (2010) found well established protocols guiding clinical practice in relation to transition. However, in the absence of robust audits or reviews it was difficult to establish how well services across the region are adhering to recommended practice. Similar to findings of the TRACK study, McGrath also highlighted the need to develop more detailed protocols, including alternative care pathways for young people whose needs fell below the thresholds for AMHS.

### *Managed transition services*

Designated transition services are generally directed to young people making the transition from CAMHS to AMHS who have a long history of service utilisation. Although not robust, evaluations of designated transition services as a transition model (JCPMH 2012) suggest some elements that contribute to effective transitions, including:

- flexibility around age boundaries

- access to a multidisciplinary team with expertise from both CAMHS and AMHS
- the provision of individual and family psychosocial and psychological interventions alongside medications
- a youth-centred and flexible approach with an emphasis on effective engagement of young people through outreach and joint working with other agencies
- expertise to treat the range of mental disorders presenting in this age group
- access to a range of services to help young people achieve independence, including education, employment and housing
- in-reach to primary care, which offers holistic health care, family practice and early detection of problems.

Managed transition models address the key elements important for good continuity of care (adequate information transfer, appropriate joint working, therapeutic and relational continuity, and engagement with adult services). This review identified 6 studies describing or evaluating programmes that adopt some level of managed transitions.

Whilst not a managed transition Verity and Coates (2007) describe a **transitional clinic** in Rotherham for young people with ADHD. The initial intake for the clinic was young people with ADHD aged 16 who were due to transition out from CAMHS. The young people were encouraged to attend the clinic with someone who knew them well. Of the 11 young people who had used the clinic, 9 had their medication regimen from CAMHS continued. Follow-up was arranged for every 6 months. Clinic staff identified unmet needs of young people with ADHD, for example young people in need of education or training opportunities, or young people requiring help with housing. They also found that some young people and their families have chaotic lifestyles that makes adherence difficult, or the ADHD caused difficulties in family relationships. The limitation of the transitional clinic approach was its focus on medication, as well as the lack of input from other professionals such as nursing, social work or psychology. In their case note review of children attending an ADHD clinic, Taylor et al., (2010) report on the benefits of specialist nurses working within their CAMH service, and propose a similar service to work with GPs in primary care settings or adult mental health services to ease the transition out of children's services for young people with ADHD. However, some have argued that given that young people with ADHD often have co-morbid conditions, specialist services devoted to ADHD may be inefficient 'in terms of capacity, skills and training' (Nutt et al, 2007, p32).

Gilmer et al. (2012) report on a quasi-experimental evaluation of a **specialised youth outpatient transition services** in San Diego for young people aged 18-24 years, delivered by staff with experience delivering services for young people who collaborate with other

services providing a range of support. As part of the service, youth-specific programmes focus on independent-living skills and age-appropriate social skills. The service is delivered in young people friendly settings such as clubhouses for young people, with trained peer mentors providing outreach support. The evaluation compared the young people attending the clinic (n=931) with a control group of young people attending a parallel standard adult clinic (n=1574) over a period of 5 years (2004 to 2009). Demographic and clinical characteristics were compared at baseline. Mental health service use was analyzed at baseline and follow-up using a quasi-experimental difference-in-difference (DID) design. Compared with traditional adult outpatient mental health programmes, the age-specific service was associated with an increased use of outpatient mental health services. Gilmer et al recommend that further research is required to assess the effectiveness of age-specific programmes for transition-age youths and how use of these programmes relate to improved clinical, educational, and vocational outcomes over time.

The **Young Adult Service (YAS)** in Connecticut was specially designed to meet the broader needs of youth ageing out of CAMHS (Styron et al. 2006). YAS is a comprehensive service including clinical, residential, case-management and planned step-up/step down care into more/less intensive services across a variety of life domains (reviewed by Paul et al. 2014). YAS aims to develop viable and durable social supports, achieve educational/vocational success and learn pro-social, adaptive behaviours and independent living skills. It emphasises the need to create and maintain stable and strong relationships with the various supports. The evaluation involved a follow-up study with a random sample of n=60 high-risk young people with moderate/severe mental illness who had aged out of institutional care or residential treatment. The longer the young person was with the programme (i.e. dose response), was linked to higher quality of life reports, greater satisfaction with services, reports of higher functioning, and lower reported loneliness. Two additional treatment characteristics predicted positive outcomes. Higher rates of strengths-focused treatment planning (SFTP) were associated with higher quality of life; and higher rates of community focused treatment planning (CFTP) were found to have fewer arrests and fewer symptoms, less loneliness, fewer mental health problems, higher functioning and greater satisfaction with services. It must be noted that given the small numbers in the study and the use of a before and after evaluation design (which cannot rule out other possible reasons for the better outcomes) further research is required to provide more conclusive evidence of the effectiveness of this approach.

In Canada, Cappelli et al (2014) carried out an evaluation the **Youth Transition Project (YPT)** based on shared management model of transition designed to provide young people with mental health and addiction problems with an individualised transitional care plan. The model involved a flexible collaborative approach to promoting co-ordination and continuity of care

between CAMHS and AMHS. The shared-care management approach aims to provide access to continuous and appropriate care during the transition period. A focus on shared care rather than shared protocols allows for more flexibility to respond to specific needs. The model usually involves a transitional advisory committee and a transition coordinator. The transition team consists of an advisory committee of key personnel from CAMHS and AMHS. The coordinator helps with the development of a transition program while also assisting with training, evaluation, and management of a transition clinic.

Cappelli et al (2014) report on an outcome evaluation of this approach, which involved a follow up study of young people (n=215) who were assessed by the co-ordinator. The study used as set of tracking tools, intake procedures and standardized questionnaires to assess (a) the transition process; (b) the young person's mental health needs; (c) the young person's individual needs; and (d) young people's transition based needs, strengths, and service planning. Nearly all the young people (n=199) were referred to AMHS. Over half the young people (n=127 59%) were seen by the adult provider. While the level of disengagement was lower than in other studies, 14% of young people cancelled services, and 19% remained on waiting lists. Of the 127 who were referred to the service, over half (n=75 59%) were referred to the project partners, and the remainder to non-project partners. There was success in reducing transition waiting times significantly over the study period, from an average of 134 days when the project began in 2011, to 69 days in 2013. Cappelli et al note that the waiting list problem illustrates the need for a service that can bridge waiting times to provide continuity of care (e.g. CAMHS continue to provide services until young people transition into AMHS). Further evaluation is required to provide conclusive evidence of the effectiveness of this approach. Cappelli and colleagues are currently designing a more robust evaluation, using different data to explore how different elements of the model work (Cappelli 2013; Cappell, Arbone et al 2014).

### *Youth and community – centred programmes*

A number of models provide multifaceted approaches to supporting young people with mental illness as they transition into adulthood. Such approaches cover multiple systems related to the transition to adulthood, such as education, health care, community and vocational areas (Clark Karpur et al. 2008; Styron et al. 2006 (see above); Haber et al. 2008).

The **Transition to Independence Programme (TIP)** developed by Clark and colleagues (Clark et al 2008; Clark Karpur et al 2008; Dresser et al 2015), as part of the Partnership for Youth Transition (PYT) initiative in the USA. The goal of the PYT initiative is to develop comprehensive models for young people aged between 14-21 years with serious mental health conditions as they emerge into adulthood. TIP aims to engage young people with emotional and behavioural disorders through relationship development, person centred

planning, and with a focus on the future. It is a 'practice model,' meaning that it can be delivered by personnel within different 'service delivery' platforms (e.g. via case management or in a team format). As part of a SAMSHA-funded initiative, the model adopts a strengths-based, individualised process with active engagement of the young person in the planning process. It provides a range of developmentally appropriate services for young people aged between 14 and 25 years.

At the heart of the TIP practice model are proactive transition facilitators (i.e., life coaches, transition specialists, or coaches) with small caseloads who act as mentors and work with young people and their families to help improve outcomes in the areas of employment, education, living situation, quality of life and community life functioning. The TIP transition facilitators use core practices in their work with young people (e.g., rationales, social problem solving, in-vivo teaching, prevention planning on high-risk behaviours), to facilitate youth making better decisions, as well as improving their progress and outcomes (Clark et al., 2008). TIP is one of the few models to be subjected to an empirical outcome evaluation study (Clark et al 2008; Clark, Karpur et al., 2008; Haber et al., 2008; Dresser et al., 2015).

Haber et al., (2008) report on the findings of the **Partnerships for Youth Transition (PYT)** initiative (Haber et al 2008), a 4-year, multisite demonstration project aimed to support five comprehensive, community-based transition programmes. PYT sites were required to use a locally driven, collaborative planning process involving stakeholder groups including transitioning age young people with SMC, their families and other members of their natural support networks, direct care providers, administrators, community leaders, and other community representatives. Each programme was allowed a great measure of latitude regarding the specific types of interventions to be used and methods for their implementation and evaluation. However, all sites were required to develop strategic plans, logic models, and programme manuals in collaboration with their respective community stakeholders to describe and guide their services. Haber et al evaluated one of the demonstration studies which used the 'Efforts to Outcomes (ETO)' to describe their change, including indicators of progress in education and employment, and indicators of challenges including criminal justice involvement and interference with daily activities because of mental health and substance abuse problems. The evaluation found that participants showed transition progress on all or most of the domains examined in all five demonstration sites, with the most consistent improvement on the indicators of educational advancement, employment progress, and the composite of these variables, the productivity indicators. The young people generally showed improvements on indicators of criminal justice involvement, mental health interference, and substance abuse interference; however, these indicators tended to improve less in certain populations (e.g., younger transitioning youth with SMC and those with disruptive behaviour disorders). The

evaluators suggest that for younger individuals, a longer period of support for employment and education-related goals may be appropriate. Similar to other studies, a major limitation of the Haber et al study is the absence of a control group in the design.

Overall, the available evidence from the evaluations of TIP (Clark et al 2008; Clark, Karpur et al., 2008; Haber et al., 2008; Dresser et al., 2015) provide evidence that the implementation of these best practice recommendations (e.g. person centred, involving family, goal setting, transition specialists) can result in improvements in real-life outcomes for young people negotiating a CAMHS/AMHS transition. However, evaluations to date rely on longitudinal follow-up with relatively small sample sizes without control groups, and provide limited data on mental health outcomes. Further research is required to provide more conclusive evidence of effectiveness. Nonetheless, lessons from the implementation research points to the importance of competency based training for the transition facilitators and peer support associates; guidance for the supervisory personnel; and capacity building to ensure continuity of a quality and responsive service system (Dresser et al 2015).

### *Mental Health Services for 14-25 year olds*

There is an emerging theme within the literature on the importance and value of youth and community centred approaches for optimal transitions (Sukhera et al. 2015; Gilmer et al. 2012). Reviews (Murcott, 2014, Sukhera et al. 2015) have noted the potential of such approaches for aligning services for adolescents and young adults. It has been suggested that if youth and adult services jointly commission services for 16-25 year olds, then they can build local capacity to meet the distinct needs of this age group (Murcott, 2014; Lamb et al, 2013). One well established model is the **headspace** service in Australia (McGorry et al. 2013). Similar models are in place in Ireland, the Jigsaw service provides mental health services for young people aged 14-25 year (O Keeffe et al. 2015), and in England, **Youthspace** in Birmingham (McGorry et al. 2013) and the **Central Norfolk Early Intervention Team (CNEIT)** (Lower et al. 2014) also adopt a more universal approaches. Such approaches are generally targeted at transition age young people with first episode psychosis, and offer a range of services. They aim to reduce some of the barriers to service access (e.g. location, stigma, confidentiality), and to maximise the factors which contribute to service uptake (e.g. address wider needs, outreach, range of therapies).

The **headspace** programme in Australia (McGorry et al 2013) is a young people focused enhanced primary care model designed to reduce the need for youth transition into adult services by providing early intervention support. 'Headspace' explicitly considers the developmental age of the young person, *and interfaces with the community in an effort to deconstruct eligibility constraints and service boundaries* (Vloet et al 2011 p. 36). The model provides a 'one-stop-shop' with (a) ease of access (e.g. self-referral for many services, online

and telephone support), and (b) a focus on the wider needs of young people (e.g. primary care, addiction services, education and employment services). To date the evidence on the effectiveness of the service is limited to a small number of external evaluations. In 2009, Muir et al prepared a report on a longitudinal study of the original 30 *headspace* centres in Australia. In a second study, undertaken by the same team, Hilferty et al used a matched comparison study[13] to evaluate the impact of the project. The two external evaluations (Hilferty et al., 2015; Muir et al 2009) found *headspace* services were attracting young people with higher than average psychological distress (75% in the Hilferty study) and who also needed support in other areas of the life, such as addiction support, and help with work etc. The most frequently occurring diagnoses for young people attending *headspace* were anxiety and depressive disorders. In the Muir et al (2009) study, almost half of those with a primary diagnosis had received at least one other diagnosis, highlighting the high prevalence of co-morbidity in young people attending the service. Both the qualitative and the quantitative data showed that most young people reported improvements in their mental health, increased insights into their condition, and had developed improved strategies for managing their conditions. Stakeholders (young people, staff and parents) consulted in the Hilferty et al. evaluation identified *headspace* to be an accessible and engaging service. The youth-friendly environment and innovative engagement approaches; the friendly, non-judgemental staff; the free or low cost service; wide-range of services provided; and practical assistance (such as transportation) were all mentioned as important factors that helped young people access and stay engaged with the service. Evaluation findings show a small positive improvement in outcomes for young people that sought *headspace* services relative to similar young people and a functional population. Specifically, the '*headspace* treatment' group recorded a greater reduction in psychological distress when compared with both the 'other treatment' and 'no treatment' matched groups over time. A second evaluation, Rickwood et al (cited by Randall et al 2016), reported a 21% clinically significant improvement in clients' mental health status in their final assessment. McGorry et al (2013) note that the *headspace* programme meets the needs of both young people with moderate levels of mental ill health, but also a substantial subset of young people with more complex, severe and enduring problems who are unable to gain access to traditional CAMHS and AMHS. In Melbourne **the Orygen Youth Health** (part of *headspace*) programme focuses on early intervention for young people with complex conditions such as psychosis, mood disorders and borderline personality disorders (McGorry et al 2013).

[13] The comparison group was separated into a 'no treatment' group of young people from the general population who had not accessed headspace or any other treatment for a mental health or drug and alcohol condition, and an 'other treatment' group who received alternative forms of mental health care between the two waves of data collection.

In Ireland, the **Jigsaw** programme supported by Headstrong National Centre for Youth Mental Health also targets young people aged 12-25. Jigsaw is a community based intervention model for young people focusing on their specific needs. Young people are actively involved in the design, implementation and review of the services to ensure they are accessible, and non-stigmatising. The model aims to strengthen the community's capacity to support its young people (McGorry et al. 2013). The majority of the young people accessing the services had moderate mental health needs, with approximately 5-10% of those engaged with needs requiring higher level mental health speciality services. This review did not identify any research documenting the role of this model in supporting young people in the transition from CAMHS to AMHS. However, McGorry et al. 2013 report that while the majority of the services users are aged 15-18 years, the programme has also engaged a significant number of young adults aged 19-25 years.

Early Intervention Services (EIS) offer specialist support for young people aged between 14 and 30 years. For example the **Central Norfolk Early Intervention Team (CNEIT)** (Lower et al 2014) in Norfolk offers support to individuals aged between 14 and 35 years who are experiencing their first episode of psychotic symptoms. A specialist youth team operates to support individuals who come into the service aged between 14 and 17 years. Young people in this age group can receive a five year service rather than a usual three year service in order to reduce the need for unnecessary transition between services and make smoother transfers to AMHS or back into primary care. As well as office based appointments, the service offers an intensive outreach model of treatment, where young people are seen in youth-friendly, non-stigmatizing venues rather than clinic or office-based appointments, with faster access to services. Appointment times are flexible, and missed appointments do not exclude the client from the service. The team accepts referrals from all agencies (voluntary and statutory), as well as self-referrals and referrals from family members. Interventions include a combination of cognitive behavioural therapy, assertive case management, support work and family work. There is a focus on promoting social activity and engagement with existing sources of educational and vocational activity, and peer and family support. The team will intensively support individuals to access other appropriate services within the community. Typically, the team will work with the individual, their families and the support system around them (e.g. school). The team maintain the care coordination role during the transition from CAMHS to adult services, ensuring continuity of care between services. Lower et al (2014) note that this early intervention in psychosis model has been instrumental in overcoming some of the weaknesses in service provision at the transition point between CAMHS and AMHS. Follow-up data show that clients seen by the early intervention youth team are a group of young people at high risk of developing long-term mental illness and social disability. Outcomes show

significant reductions in not only psychotic symptomatology, but also co-morbid anxiety and depression, as well as improvements in social recovery. The authors note that at the end of their time with the service, the majority of clients (64%) are discharged back to the care of their general practitioner and only 9% transitioned to adult services, which indicates that the team successfully managed to reduce the complexity of needs and difficulties associated with this client group. The study was limited in the small numbers (n=57 baseline, and n=34 at discharge), and in the absence of a control group it is not possible to provide conclusive evidence of effectiveness.

Sukhera et al describe the advantages of community based approach as being youth focused and community based with potential cost savings, but the disadvantages include the initial high cost to establish the programmes, and the introduction of a possible second transition point for the young person (e.g. transition at age one 12-15, and again at 25) if they transition to adult service. On the other hand, McGorry et al 2013 argue that such models

> *... have been built around a recognition of the major weakness of the health system for young people with mental ill health, consequent major unmet need, and a shared commitment to improve the accessibility, scale and cultural/ developmental appropriateness of mental health services to young people and families, and to reduce the need for harmful transitions at critical points in the young person's development (McGorry et al 2013 pS34)*

### *Involvement of peer mentors*

A small number of studies have highlighted the potential importance of the support from peers. Four of the programmes described above (TIP, headspace, Youth Outpatient Service, CNIET) included some element of peer mentoring. As part of the Youth Outpatient Service, Gilmer et al (2012), trained peer mentors provided outreach to young people to encourage them to access the services. In the UK, an initiative in Cambridge is currently developing a transition preparation programme which involves a Transition Peer Support worker (Dunn et al. nd).

In response to the ImROC initiative recommendations (Sheppard et al. 2008) for the use of peer support workers as a means of driving forward recovery orientated change, Rotherham, Doncaster and South Humber (RDaSH) NHS Trusts introduced a pilot study with Peer Support Workers (PSW) to support the transition from CAMHS. A mixed methods approach (e.g. focus groups, interviews and e-survey) was used to evaluate the approach (Oldknow et al 2014) which found that the PSW role was subject to local variations. In one area, only a limited number of young people needed support with the transition, so the PSW worked with young people who needed a supportive mentor. The study found one of the greatest challenges to implementing the service was the attitude of staff in CAMHS and AMHS. Some reported suspicion or lack of clarity of the role and its benefits, whilst others voiced concerns over the limitations of sharing experiences, some of which may be traumatic, and may risk making the service user feel worse or decrease the mental wellbeing of the PSW. While a minority of staff were initially resistant, this changed and staff actively sought out PSWs to be involved in cases. This beneficial shift was attributed to the attitudes and personalities of the people employed. While the authors considered the model to have assisted the transition process, as the evaluation was based on a small scale predominately qualitative study, further research is required to provide more conclusive evidence of effectiveness.

**Box 6.8** Summary of key feature of models

| Elements of programme / service | TIP | YTP | headspace/ Orygen | Jigsaw | Outpatient Clinic | YAS | Transition clinic | CNEIT |
|---|---|---|---|---|---|---|---|---|
| Use of protocols | | | | | | | Yes | |
| Youth friendly & appealing services (setting etc.) | Yes | Yes | Yes | Yes | Yes | | Yes | Yes |
| Strengths based | Yes | | Yes | Yes | Yes | Yes | | |
| Active engagement of YP in design & review of services | Yes | Yes | Yes | | | | | |
| Goal setting | Yes | | | | Yes | | | |
| Address wider needs e.g. education, vocational, health | Yes | Yes | Yes | Yes | Yes | Yes | | Yes |
| Promote community supports/positive relationships | Yes | | Yes | Yes | Yes | Yes | | Yes |
| Builds skills and competencies | Yes | | | | Yes | Yes | | |
| Involve transition specialists | Yes | Yes | | | | | | |
| Involve family/carers as advocate | Yes | | Yes | Yes | | Yes | | Yes |
| E-learning /technology | Yes | | Yes | Yes | | | | |
| Use of mentors/peers | Yes | | Yes | | Yes | | | Yes |
| Interagency working | Yes | Yes | Yes | | Yes | | | Yes |
| Developmental appropriate services | Yes | Yes | | | Yes | Yes | | Yes |
| Co-ordinated services | Yes | Yes | | | | Yes | | Yes |
| Build staff competencies | Yes | Yes | | | | | | |
| Systems approach | Yes | Yes | Yes | Yes | | | | |
| **Strength of evidence of effectiveness** | **W** | **W** | **M** | **N** | **M** | **M** | **W** | **W** |

Abbreviations for overall strength of evidence
N: No evaluations identified (relevant to mental health outcomes)
W: Weak evidence (i.e. lack of baseline data, no comparison group, no relevant outcome data)
M: Moderate level evidence (i.e. longitudinal data, comparison groups, relevant outcome data)
S: Strong (i.e. randomised controlled trial, large sample size, validated outcome measures)

### *Models of transitional care for young people with chronic health conditions*

In the recent Cochrane review, Campbell et al (2016) only identified four studies evaluating the effectiveness of interventions designed to improve the transition of care for adolescents from paediatric to adult health services. From the included studies, one found evidence of improvement in young people's knowledge of their condition, and a second noted improvements in self-efficacy and confidence. However, given the small number of included studies (each with short follow-up), the reviewers concluded that the overall certainty of the body of this evidence was low as the data provided was inadequate to determine either the full impact of the interventions or the sustainability of the outcomes.

In their broader scoping review to identify models of transitional care for young people with chronic health conditions, Watson et al (2011) present an analysis of 18 transitional care models. Most of the papers described how the service was provided, but few described how the service was experienced by the young people or the services providers. Similar to mental health services, there was limited reporting of any evaluations of the services over time, although there was some service monitoring. However, one model (Betz and Redcay 2003) for young people with special healthcare needs including cerebral palsy, had what Watson et al describe as high coherence with:

> *evidence that staff understand the need to be flexible about the timing of transfer to adult services. Transfer should be made on the basis of need and not on the grounds of reaching a specific age (*Watson et al 2011 pg 783).

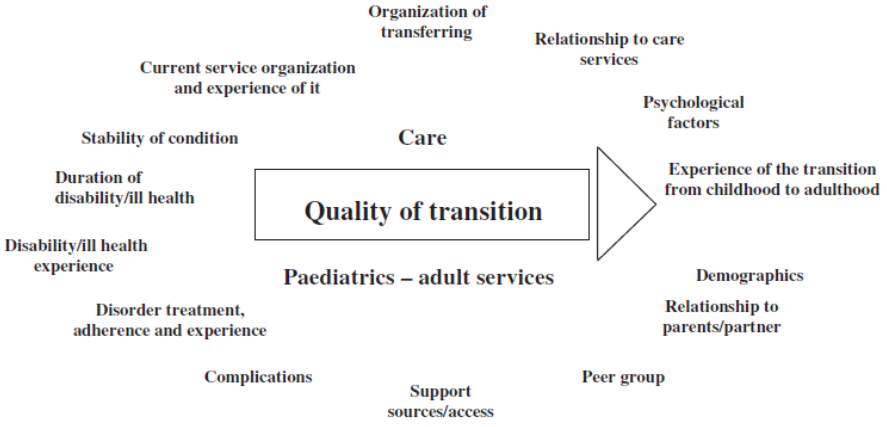
Betz and Redcay (2003) reported that service staff had an understanding of the need to consider all aspects of the young person's transition needs including healthcare, education, community living, employment and social leisure activities (see community based programmes above).

Watson et al (2011) identified 10 transition categories which overlap with the four categories described in Box 6.4b including: timing (e.g. timely and flexible to respond to developmental stage); individual focus (e.g. person and needs centred; involve YP and family/carer); considers other areas of transition (e.g. lifestyle, psychosocial/educational/vocational as well as medical); preparation for adult services (e.g. YP provided with comprehensive information/advice/education); skills training (e.g. YP provided with opportunity to gain independence and take responsibility for own healthcare choices; self-management and advocacy skills); delivered by staff trained in working with YP and a knowledge of transition issues; service development (e.g. involvement or signposting to other relevant services; multiagency working etc.); sustainability (e.g. outcome measures) and evaluation (e.g. have measureable outcomes, regular review and evaluation). Notably, Watson et al 2011 found

that despite the general agreement about the importance of effective transitional care, there was a paucity of evidence to inform best practice about both the process of and what constitutes effective transitional care. Thus, there is an urgent need for research to evaluate current transitional care practices for young people with chronic health care needs.

One of the earlier reviews on the continuity of care from children's to adults' services (While et al 2004) highlighted the complex nature of this process. Figure 6.2 provides a summary of the different elements that impact on the quality of the transition.

**Figure 6.2**: Factors influencing the quality of the transition from paediatrics to adult services




Source: While et al (2004)

In a more recent study, Suris et al (2015) used a Delphi approach to identify 6 elements for a successful transition for young people with chronic conditions. These elements echo the themes above, and include: the assurance of a good co-ordination; early planning for transition (at least one year in advance); discussing with patient and family about self-management; including young people's views and preferences in the transition planning; if developmental appropriate, seeing the young person alone for at least part of the appointment; and identifying an adult provider to take on the young patient before the transition.

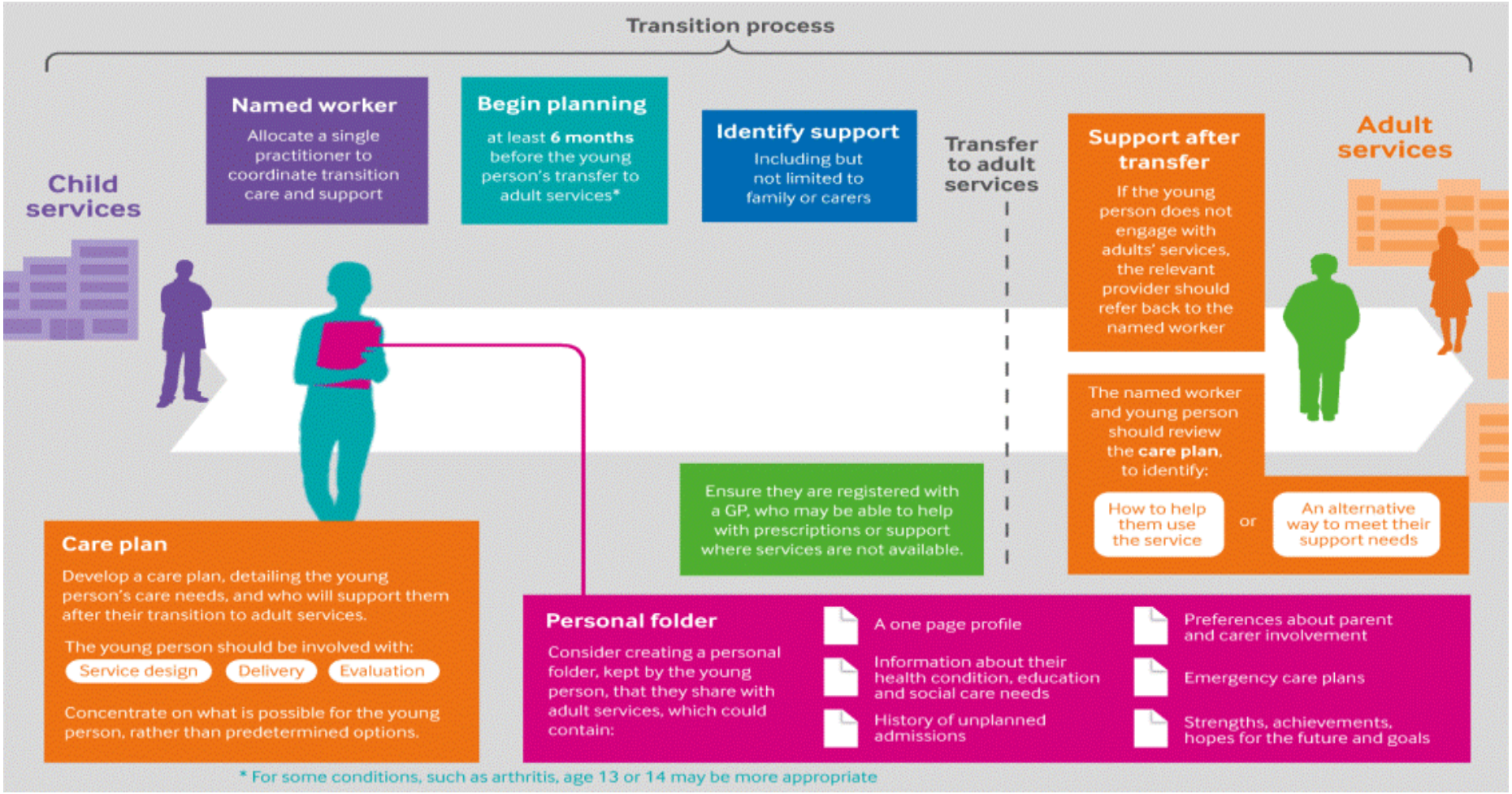
In an effort to improve the transition experience for young people with chronic conditions, a team at Southampton's Children's Hospital have developed the ***Ready Steady Go*** (RSG) toolkit[14]. RSG uses a holistic approach addressing the medical, psychosocial and vocational needs of the young people within young people friendly services, and also recognises that the young person's family/carers are essential to the delivery of effective transition. A service evaluation (Cable and Davis, 2016) of the 'Ready Steady Go' transition programme with YP

[14]http://www.uhs.nhs.uk/Ourservices/Childhealth/TransitiontoadultcareReadySteadyGo/Transitiontoadultcare.aspx

with type 1 diabetes compared the outcomes of using the structured RSG programme with those where the structured programme was not in place. The study found more than a 50% reduction in diabetes related hospital admissions and an increase in the number attending adult outpatient clinics, compared to those who had participated in structured transition programme.

A recent paper by Singh et al (2016) summarises the messages from the NICE (2016) guidance on transitions. Figure 6.3, below, depicts a sufficient summary of the key stages in the transition process from child to adult service.

Figure 6.3: Summary of the NICE (2016) guidance on transitions




Source: Singh et al (2016) http://www.bmj.com/content/353/bmj.i2225

### *6.6.3 Ongoing research to evaluate transition models in mental health*

The current evidence base on approaches to support young people with mental illness as they transition to adulthood, and for some into adult services, is limited. The evidence is based on weak longitudinal studies with small samples, each using different measures to assess effectiveness.

It is evident from this review that one of the key priorities for research is the need to establish an evaluation framework that is sufficiently robust to evaluate the effectiveness of the different models of care to support transition. Central to this task is the agreement of a set of process and outcome measures.

Three programmes of work are underway that will go some way to fill the evidence gaps to help inform future research and practice. For example, the large scale collaborative research MILESTONE[15] project aims to collect evidence systematically in order to determine care gaps in current mental health services across healthcare systems in Europe. Whilst the central aim of the study is to evaluate an innovative transitional care intervention, and to develop a sustainable and standardised best-practice transition model, the project has a number of work programmes including: the development of Patient Reported Outcome Measures (PROMs) and a data capture and monitoring system; and the development of a Transition Readiness and Appropriateness Measure (TRAM) that identifies high-risk, high-need cases for whom transition to AMHS is critical. The managed transition model will be evaluated using a nested cluster randomised controlled trial (cRCT). The study will delineate the transition journey of young people across eight EU countries, and identify predictors of good and poor transition. Further research is being undertaken by the Canadian CHEO team (Cappelli et al 2015) to evaluate the effectiveness of a shared management approach to transition. The project has developed a logic model to describe the theory of change and to depict the anticipated outputs, and outcomes of the approach.

A third programme of work is being undertaken by a team of researchers at the Transitions project at McMasters University in Canada (Randall et al 2016). The first phase of the project involved a series of systematic reviews (Embrett et al 2016; Mulvale et al 2016) and the development of tools to translate the research findings to practice[16] (Randall et al 2016b).

[15] http://www.milestone-transitionstudy.eu/
[16] http://youthtransitions.degroote.mcmaster.ca/

## 6.7 Summary of Evidence Review

### *6.7.1 Review Question 1- Messages from national and local guidance*

This review question focused on the key messages emerging from national and local guidance and policy with relevance to the transition from CAMHS to AMHS. A number of key themes reoccur in this body of literature. National guidelines and guidance documents highlight the importance of:

- adopting a human rights approach
- delivering young people friendly services (person centred and enabling)
    - the involvement of the young person, and where relevant, the parent/carer in review process
- preparation and planning for transition to ensure smooth transitions
    - supported by keyworker or transition co-ordinator
- collaborative working
    - local policies and transition protocols agreed between CAMHS and AMHS
- flexibility to reflect developmental readiness and wider support needs of young person
- continuity of care (with particular attention to young people with ASD, ADHD and eating disorder)
- supported by staff with training in adolescent care
- good information transfer
- the involvement of young people and parent/carers in the design and review of services
- review and audit of transitional processes

### *6.7.2 Review Question 2 - What is needed?*

Poor transitions from children's to adult services result in poor health and social outcomes such as high drop out of care and/or poor adherence to medication, resulting in increased emergency presentations and longer term health and social problems (Watson et al 2011). Over the past decade, both policy and research describe the difficulties young people experience during the transition from children's to adult services. Primary research highlights the need for person-centred care, planning for transition (e.g. care plans, joint meetings, the use of protocols etc.) and the involvement of the service users and family/carers.

The synthesis revealed that young people in transition to AMHS are experiencing parallel health, educational and social transitions, and as such have a range of social, developmental, as well as emotional needs. At the point of transition to adult mental health, services tend to focus on the clinical needs, with young people's wider social and developmental needs often being neglected. The findings from the research with young people, their parents/carers, and service professionals provide evidence of the ongoing need for young person centred mental

health services. Services that address the unique needs of late adolescence and early adulthood in order to provide the support required within a recovery oriented model of care.

Overall this body of research identifies the barriers to and facilitators for successful transitions. The barriers to good transitions include:

- limited funding and/or limited resources resulting in fewer young people being referred to adult services
- poor planning and preparation
- poor information transfer
- lack of mutual understanding of the different services e.g. CAMHS perception AMHS will not accept referral and different philosophies of care
- rigid cut-offs / boundaries for transitions
- poor co-ordination
- lack of collaboration
- focus on clinical need without consideration of wider support needs

The facilitators to good transitions include:

- flexibility to reflect young person's developmental stage and needs
- planned transitions that involve and prepare the young person and their family/carer
- co-ordinated transition
- positive relationships between young person and service provider
- continuity of care (therapeutic care)
- young people friendly services e.g. setting, information, confidential etc.
- young people focused care / programmes designed specifically for the developmental needs of the young person
    - approaches to address the wider support needs of young people e.g. skills building, help with education/training, housing, finance etc.

Young people with ADHD, ASD, eating disorders, and young people leaving care were identified has having specific support needs. Case reviews and secondary analysis indicate that not all young people with ADHD/ASD are referred to adult services. Consideration should be given to providing services for transition age young people with mild or moderate mental health or neuro-developmental conditions who do not meet the eligibility criteria of adult services.

In order to ensure the specific needs of young people transitioning out of CAMHS staff require training and support:

- to deliver youth centred services during the transition period
- to gain knowledge and skills in providing support for young people and/or adults with specific conditions such as ADHD/ASD.

### *6.7.3 Review Question 3 – What works?*

Whilst there are numerous documents providing guidance and/or advice on supporting the transition from children's to adult services, there is limited evidence from robust studies on how best to facilitate transitions for young people. Whilst it is not possible to provide a conclusive statement on 'what works' in supporting the transition from CAMHS to AMHS, the findings from the evidence to date point to some features associated with more successful transitions including:

- transition-related meetings (transfer planning meetings, joint working, information transfer) between caseworkers, youth, and parents/carers to establish good relationships prior to the transition and to promote continuity of care (Embrett et al 2016). Examples from the evidence include the 'wraparound' or caseworker process described in studies by Davis and Sondheimer (2005), and Stryron et al., (2006), and the outpatient clinic evaluated by Gilmer et al., (2012)
- approaches to help youth achieve more independence and control of their health (Gilmer et al. 2012; Clarke et al 2008; Dresser et al 2015) and overall life (Styron et al. 2006; Embrett et al 2016)
- collaborative working between adult providers and youth and family during the transition period (Gilmer et al 2012; Cappelli et al 2014)
- a transition co-ordinator (see Cappelli 2014) to promote a higher profile of young people in adult services, to shape the process of referrals across services, and improve the scope for preventive work (Singh et al 2010; Embrett et al 2016)
- capacity building through training and education was considered necessary to engage professionals in these activities (identified by Hovish et al. 2012 and included as part of the TIP model described by Dresser et al 2015).

Other suggestions for future service developments include the use of peer support workers (Gilmer et al 2012; Mulvale et al 2016; Lambert et al 2014; Oldknow et al 2014), and the increased use of technology (Embrett et al 2016; Randall et al 2016) to support young people during the transition. Alternative models of care, such as the community based models adopted by *headspace* and the early intervention service CNEIT, provide young people aged 14 to 25 with mental health services in youth friendly environments beyond adolescence and into early adulthood. From the available research evidence it is not possible to determine if such services improve the longer term mental health and wellbeing outcomes of the young

people who ultimately transition to adult services. But it has been argued, that offering a service for 14-25 year olds, presents a new pathway that will be *robust at the period of maximum risk both of discontinuity of care in early onset disorders and of the peak of emerging mental disorders* (Singh and Tuomainen 2015 pg 360).

Some authors (Munoz-Solomando et al. 2010) suggest that a single model of transition may not be suitable for every organisation. Sukhera et al. (2015) recommend that:

> *an ideal model would likely incorporate various elements of each along with empowerment of service users and caregivers to navigate the system effectively. (Sukhera et al. Pg 276)*

To date, there is only limited evidence from robust studies on how best to facilitate transitions for young people between CAMHS and AMHS. As Singh and Tuomainen (2015) conclude:

> *Identifying what is needed is mbouch easier than actually providing it. In current clinical practice there is no consensus on who can be discharged on reaching the transitional boundary, who should receive transitional care, how this care should be delivered, what outcomes should be measured. (*Singh and Tuomainen 2015 p 359)

Nevertheless, clear messages emerge from the review and primary level evidence pointing towards the need to implement action at three levels: system, organisational and programmatic levels (Sukhera et al 2015; Davidson & Cappelli 2011). Action implemented at a systems level will require commitment and support at a policy level in order to ensure the resources are available to provide effective services during the transition phase. A top-down approach is required to ensure sufficient funding and commitment is given to providing young people friendly transitions (Davidson and Cappelli 2011). At the delivery level partnership work involving young people, their parents/carers, service providers and commissioners is also required to ensure services are designed to meet the needs of young people.

A high level of commitment is also required to ensure that staff are offered, and receive, the training and support to implement change. At an organisational level, leadership is required from both commissioners and senior management to support collaborative and effective partnerships between CAMHS, AMHS and the community and voluntary sectors. At the programmatic level (or service level) the importance of user and family involvement is central to achieve person centred care. Sufficient planning and resources are required to evaluate, audit and review different models of support.

In order to establish the effectiveness of different models of care, agreement is required on the outcomes of such services, and how these are best measured and recorded. There

appears to be a large international evidence base that supports the need for well planned and flexible transitions for young people as the transition from CAMHS to adult services (specialist or primary care). In order to ensure that such services are delivering quality and effective care, agreement on key process and outcome measures is necessary. Outcome data are essential in providing clinical and financial evidence for the cost-effectiveness of such approaches. Large-scale evaluations of the current models to bridge the gap between CAMHS and AMHS will also further this progress in the youth mental health field.

# CHAPTER 7: CONCLUSIONS AND RECOMMENDATIONS

## 7.1 Conclusions

Evidence suggests that adolescent engagement with mental health services is problematic, with poor attendance and high rates of service refusal. Disengagement from services is associated with poor outcomes and high social costs. Thus, when young people fall through the net at this stage, they are likely to return with deeper, more resistant problems. Blum et al (2003) described healthcare transition as '*a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centered to adult-oriented healthcare systems*'. We argue that the transition process from CAMHS to AMHS is a 'thin-ice' pathway with the potential for slipping, stumbling or disappearing entirely.

This is the first study in Northern Ireland to examine the transition pathways and experiences of young people in mental health care and which provides an exploration of structural and other barriers to providing a relatively smooth and person-centred transition from CAMHS to AMHS. It is worth stating straightaway that most of the IMPACT participants, service users and family members, were deeply appreciative of the overall service that they received and were highly complementary about staff within CAMHS. Service users with some experience of AMHS had few complaints.

From our case note analysis of the transfer from CAMHS to AMHS, similar to the TRACK study in England, we found that most people referred to AMHS were accepted – negligibly few people referred by CAMHS were rejected by adult services. Indeed, a higher number of service users considered for transfer to AMHS, refused to go. These findings contrast with those of the I-Track study of transition in the Republic of Ireland where less than a third of those perceived to have on-going mental health needs were referred to adult mental health services (McNicholas et al. 2015).

Perhaps of greater concern was the quality of the transition process, where we found that none of the cases transferred from CAMHS to AMHS met all four criteria of an optimum transition. Few people had a transition-planning meeting or a period of parallel care. Moreover, we noted that the transfer of information between services was uncommon.

The IMPACT study was undertaken at a time when services were also in transition or, at least, that is, most had begun to improve services for young people following a report on CAMHS in Northern Ireland (RQIA, 2011) in which the authors noted the presence of transition protocols in 'most Trusts' but were unable to provide evidence on their implementation. Additionally, since the IMPACT study was commissioned, more research evidence on the CAMHS-AMHS transition has been published (8-12) and services have continued to respond to these findings

and to other pressures. Thus, we know that while mental health services in Northern Ireland have striven to implement recommendations made within the Bamford Review (Bamford 2006), referrals to CAMHS services have grown substantially over this period in the midst of financial cuts. Therefore, from the outset, we knew that the data to be gathered on services and service use was more than a 'snap-shot' of how things were. Rather, we understood the study as an opportunity to consider how services were evolving to meet transition needs and pressures, and how clinicians and service users perceived the challenges to providing more effective services as they crossed the boundary.

There does seem to have been recent progress made in these areas with the development of transition protocols and panels in various Trusts. It was described how, the transition process has become much more person-centred, rather than being dictated by the quality of relationships between staff within CAMHS and Adult Services or the vagaries of power dynamics in any particular transition meeting. The introduction of transition protocols and panels seems to have, at least partially, eliminated the need for CAMHS keyworkers to 'fight their corner' when it comes to presenting cases.

However, the general picture that emerges from the IMPACT study is that the five Northern Ireland H&SC Trusts continue to show considerable variability in how they meet the transition needs of young people. Without a regional policy or protocol with regard to the Transition each of the five HSC Trusts has developed their own Protocols albeit with a good degree of shared key standards. The Belfast Trust and the South East Sector share the same Protocol with local variations. Moreover, the Western Trust includes a separate section on the Transition of young people with ASD to adult services, and the Belfast and South Eastern include the specific guidelines for those making the transition from local CAMHS to the Early Intervention Team. Even within individual Trusts there is no consistent or singular approach to dealing with the transition. Thus, not all Trusts have a transition panel; in those that do, there is variation in composition, policies and procedures. One transition panel will review all cases that arrive at the transition stage; another will consider only those cases considered to have complex needs. Similarly, while all Trusts have transition protocols, many clinicians have not read them and/or are unclear about their content. There is also no consistent transition approaches for people with ADHD or ASD, who consistently fall through the service gaps. The lack of provision for those with ADHD in adult services has meant that CAMHS are obliged to retain these young people if they are on medication. Available data (recorded or estimated) indicate variation in the numbers of accepted referrals to adult services. The NHSCT estimated that all referrals are accepted, but the BHSCT estimated that a quarter of referrals are not accepted. The proportion of accepted referrals is lower in the WHSCT, which estimated that 17% to 38% potential cases are not accepted by adult services. The CAMHS team in ND&A estimate that

only a third of potential referrals had been accepted. Again, although we found considerable variation between the Trusts in the proportion of service users rejected by AMHS, we suggest a level of caution due to the instability of record-keeping in relation to service transition.

Geography and resources also play a considerable role in determining the options available to service users, clinicians and families, and the potential for efficiently gathering health professionals and other stakeholders for joint meetings. Thus, Belfast and the Northern H&SC Trusts have much better access to a range of well-established voluntary sector organisations compared to the Western Trust, where the widespread rurality also impacts on arranging meetings. The concentration of population and resources in Belfast makes it the obvious choice for developing specialist young person's services that would be impossible or at least, not cost-effective elsewhere. Combined with the variation in the Trusts' commissioning priorities and interests, it is fair to say that the type of resources and their distribution across NI, lack standardisation and often appear unfair, especially to families.

We found a consistent anxiety among young people and their families about what to expect when they move to adult services, and poor communication with service users and their families is a major determinant of satisfaction with services. A communication vacuum heightens the level of anxiety and stress experienced by young people (and their families) as they approach the transition boundary. We found that the fears about adult services are mostly hearsay rather than facts. Commonly these are stigmatising perceptions of adult services, which gain currency among service users to the detriment of engagement and treatment. Health professionals assured us that this information is fully explained. The dissonance highlighted here may be about *what* is explained and *how* it is conveyed. Thus, it is likely that keyworkers do discuss adult services with young service users but we found no evidence of any written materials in any format.

The in-depth interviews with service users and their families highlight that there is no singular and consistent perspective among young people and their families in relation to how transition to adult services are viewed. While some young service users experience considerable anxiety about the loss of close and familiar relationships with services and people, others are keen to assert their transition to maturity and independence, to be in control. Moreover, the needs of young people, in large part determined by their individual mental health problems, are also likely to dictate their attitudes and responses to life in general, and adult care more specifically.

The problem of service fragmentation is a perennial one (Strange 2009). However, the discussion of fragmentation generally refers to the range of discrete specialist services that are seldom integrated for the care and treatment of the whole person. The division of

psychiatry and mental health services into pre and post adolescence creates the illusory impression that these services deal with different problems and different people. And, of course, this is not the case. Nevertheless, there are quite distinct organizational behaviours, values, norms and attitudes on either side of the division sufficient to highlight divergent organisational cultures within psychiatry. Our interviews with a range of stakeholders, including the professionals, point to differences in type, style and availability of service provision. Mostly, such differences have a clinical logic. For instance, CAMHS are reticent to provide definitive diagnostic labels and this makes sense when young people commonly present with several and undifferentiated symptoms. Pharmacological treatment within AMHS is contingent on diagnosis. However, it would also be unwise to suggest that CAMHS are pharma-phobic; our findings suggest otherwise.

Of greater concern perhaps, was the commonly voiced concern by clinicians in CAMHS and AMHS that they knew very little about each other's services, what was available, and where. While Transition Panels may illuminate some of this void, it may be that only those clinicians who attend such panels obtain a sense of service availability, albeit limited.

## 7.2 Strengths and limitations of the study

### *Strengths*

Unlike other similar studies of the transition from CAMHS to AMHS (Paul et al. 2015), IMPACT was able to obtain the greatest number of cases that were active in CAMHS across one complete region, covering all the relevant mental services, and provided the most comprehensive and robust evidence of young service users' journeys on the transition pathway. Additionally, while relatively diverse, in terms of geography and urban-rural populations, the current study population was ethnically homogenous; this may limit generalisability to other, more diverse contexts but provides a considerable level of certainty. The in-depth interviews with service users, families, clinicians and managers, some of which had a longitudinal aspect, provided important insights into the process, highlighting the complexity of different psycho-social needs of service users while offering a better understanding of structural fragmentation and cultural barriers to easier transition.

### *Limitations*

The IMPACT study would not have been possible without the permission and support of the Trusts and while the navigation of the Trust R&D governance processes was challenging, we appreciated their guidance and help. However, despite the assistance given by Trusts, we found it difficult and time-consuming to deal with the prevalence of 'hard to locate' patient notes and the uncertainty among some Trusts about which patients and how many were regarded as eligible for transition. Additionally, the different, sometimes incompatible,

electronic hospital records systems used by Trusts created delays in data collection and introduced a degree of uncertainty into the process. Although, we believe that we were able to obtain almost all of the relevant case notes, we accept that the information contained within them may be incomplete or may not precisely reflect all the facets of service provision. For example, clinicians often differ in the quality and quantity of their medical notes (Health Informatics Unit, 2008).

We were unable to obtain in-depth interviews for all service users and families at three time points. Despite this, we feel that we were able to get a reasonable understanding of change over time, particularly in relation to differences between expectation and actual experience.

## 7.3 Recommendations

### *1. Written information on Adult Services and the transition process*

We recommend the development of information materials and educational tools about both the transition process and adult mental health services, and versions should be available and appropriate for young service users and families, respectively. Generic information should be available in leaflet form and on Internet platforms, providing basic knowledge about the transition process, what happens in AMHS, and about access to local statutory and voluntary mental health services.

Person-specific information detailing the process plan and the key stakeholders should also be provided to service users and families when the transition process begins.

Communication and educational tools are likely to obtain greater credibility with service users if young people are involved in the design of leaflets and web-based videos. We would like to see such tools developed with a range of young service users, possibly diagnosis specific. There is a need for evidence on the effectiveness of such tools.

### *2. Communication between services*

Despite the availability of protocols that highlight the importance of inter-agency communication, we found that the provision of service user case notes or case summaries from CAMHS were not routinely passed on to the new keyworker in AMHS. It is not clear if this happens due to administrative barriers or adherence to custom and tradition. At the very least, a comprehensive case summary should be provided to AMHS at the outset of the transition.

Although we found some instances of joint appointments (across the transition period), these remain exceptional rather than commonplace. Joint appointments appear to be an effective

means of underpinning continuity of care by establishing consensus about the process and the therapeutic goals. Additionally, they may assist in dispelling anxiety about AMHS and building trust with the new service keyworker. How to address the mutual incomprehension of clinicians on either side of the service border about each other's services will require further exploration by the relevant colleges and professional bodies in psychiatry, nursing and social work.

### *3. Service User and Family Support*

**Peer Mentors:** The creation of a Peer mentorship scheme within CAMHS was perceived by staff as a potential solution to tackling some of the psychosocial and service-related problems of young service users. While such a scheme might appear useful, there is scant evidence on the feasibility of building a peer-mentorship service for this age group and how sustainable will it be. More information is needed on how mentors could be recruited and trained. For example, how many service users are likely to be interested? What degree of matching is required? What level of support will mentors require? More research is needed on the feasibility, effectiveness and sustainability of peer mentors. While this type of intervention is currently underway elsewhere in the UK, there is no evidence from robust studies but the available evidence looks promising (Oldknow 2014).

**Parents' support group:** Other suggestions for support during transition included the establishment of a family support group. While family support services already exist within the voluntary sector, it may be possible to establish transition-specific family support groups with an educational contribution by CAMHS and AMHS. Parents sometimes feel, or perhaps are, removed from discussions about transition. A low-cost telephone or email advice service could be developed for the benefit of parents who are unsure of their role, or rights, across the transition process.

### *4. Separate services for 16-25 year olds*

There was considerable discussion, mainly from practitioners, but also members of the community and voluntary sector, service users and parents/carers, about the possibility of developing a service to bridge the gap between CAMHS and AMHS, much like the Early Intervention Service, which currently exists in the Belfast Trust. This conversation was addressed extensively during the IMPACT workshop, attended by a wide range of stakeholders in the project including service users, practitioners and members of the community and voluntary sector. Service users and practitioners proposed the development of a service for people 16-25 years, closing the considerable gap between the cultures in CAMHS and adult services. As described in Chapter 6, different models of service directed to young people aged 16-25 have been implemented in other countries (e.g. headspace and

Orygen in Australia) and some models are in operation in the UK and Ireland (e.g. Youthspace in Birmingham and Jigsaw in Ireland). In addition, separate transition services have been developed on other parts of the UK (e.g. The Wirral 16-19 transition service; City and Hackney extended CAMHS). The Sheffield ADHD transitions clinic has a range of services for young people with ADHD, intended to create a smoother resolution to service and social problems (Crimlisk, 2011). It was, however, acknowledged that introducing a service for 16-25 year olds would mean that rather than one transition, young people entering the services before the age of 16 and who continue in services beyond the age of twenty-five would have two transitions to make. Moreover, while there are apparent advantages to an extended or transitional youth service, we currently lack robust evidence on their effectiveness. However, as described in Chapter 6, research led by Professor Singh (CI) and currently underway in seven European countries will provide evidence on how best to provide transition services.

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# APPENDICES

# APPENDIX 1 ACKNOWLEDGEMENTS

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# APPENDIX 2

## SUMMARY OF BAMFORD REVIEW (2006), McCartan Report (2007) and RIQA Review of CAMHS (2011)

### *The Bamford Review (2006)*

The first review, prepared by Prof Bamford and colleagues, sets out a strategic vision for the development of a service for children and young people with mental health problems. Based on the principles of the promotion of good mental health and the provision of accessible and effective treatments; the report contained 51 recommendations, of which a number relate directly to the transition from CAMHS to AMHS. The review states that:

> *The transfer of care between child and adolescent services and adult services usually occurs around the age of 18. There may be circumstances when it is in an adolescent's best interests for a CAMH team to continue to care for them beyond the age of 18 while plans for transfer to adult services are put in place. Conversely, it may be appropriate to transfer some adolescents to the services for adults before their 18th birthday. Care pathways and protocols should be developed between adolescent and adult mental health services to allow optimal patient care during the transition from one service to the other. In all cases it is vital that collaborative arrangements between adult mental health services and CAMH services is put in place to ensure that the suffering in a child or parent does not go undetected or untreated.* (Bamford Review page 52)

**Bamford Review Recommendation 23** The interface between CAMH services and adult mental health must be addressed and more effective collaborative arrangements established to ensure that the suffering in a child or parent does not go undetected or untreated. Para 6.11

The Bamford Review recommended that care pathways and protocols be developed to ensure optimal patient care between CAMHS and adult services. In addition, the review identified that transfer to adult services will usually occur around the eighteenth birthday, however, flexibility is required to ensure the best interest of the young person is considered. The review also indicated that effective collaboration between adult and CAMHS will also ensure that the mental health and any other relevant family circumstance will be considered.

### *The McCartan Report (2007)*

The McCartan Report was prepared in response to a complaint by Mr and Mrs McCartan regarding the death of their son, Danny McCartan in April 2005. The investigation panel examined the treatment and care offered to Danny McCartan and his family and identified 12 key areas for improvement. A significant finding in the McCartan report was the poor transitional arrangements for young people moving into adult mental health services. It also highlighted that patients were not always engaged in the process or involved in the decisions surrounding transfer.

### *RQIA (2011) Review of CAMHS*

In 2010 a review of CAMHS in Northern Ireland was conducted by Regulation and Quality Improvement Authority (RIQA 2011). The review examined the quality and availability of a range of services and professional groups involved in the delivery of specialist mental health care for children

and young people in hospital and community settings. The RQIA review team examined 2 themes with relevance for the transitions from CAMHS to AMHS:

1. the quality and safety of care of young people admitted to adult wards; and
2. the quality and safety of existing transitional arrangements between CAMHS and adult service.

In the absence of specific regional CAMHS standards, the RQIA review team used the standards produced by the Royal College of Psychiatrists (RCP), the National Service Framework for England (DoH) and the Final Review of CAMHS as a measurement of best practice. Relevant NI legislation including The Mental Health (Northern Ireland) Order (1986), and The Children (Northern Ireland) Order (1995) provided the underpinning legislation throughout the review. The United Nations' Convention on the Rights of the Child (UNCRC) also provided the context of a rights based approach for the RQIA's review.

Five criteria were applied in the review of the transition from CAMHS to AMHS. Table 1 below presents a summary of the RQIA reviewers' assessment of each Trust area's level of achievement for each criterion. The criteria include smooth transitions, use of protocols, explicit policies regarding the transfer of clinical responsibility, involvement of service users, parents/carers; and effective transfer of information.

Table A2: Summary of RQIA (2011) assessment of progress in achieving individual criterion regarding good transitions.

| Criterion | BHSCT/ SEHSCT | NHSCT | SHSCT | WHSCT |
|---|---|---|---|---|
| 3.1.1 Young people with ongoing mental health needs should be guaranteed a smooth transition into adult mental health services. | Partially achieved<br>Draft protocols in place.<br>Smooth transitions do not always take place.<br>Some disparity between two areas. Interface meetings set up to resolve differences in opinions on referrals to adult service.<br>No transfer to adult service before 18. | Substantially achieved<br>Policy and protocols in place. During transition to AMHS, staff from CAMHS continue to work with YP to ensure seamless transition. | Substantially achieved<br>Protocols in place. Planning in advance of transfer.<br>Complex cases considered for transfer before 17 years and 9 months. MDT meeting discuss transfer of YP before 17 yrs 8 months.<br><br>Under age 18 referrals directed to adult mental health team booking and triage. (Process confirmed in focus group) | Partially achieved<br>Transitions via interface meetings at managerial and clinical levels. |
| 3.1.2 Protocols governing the movement of service users between (CAMHS) and adult services should be developed. | Partially achieved<br>Draft joint protocol with flowchart of care | Substantially achieved<br>Protocol in place. | Substantially achieved<br>Joint protocol in place, which | Partially achieved<br>No protocol at time of review (only outline draft). |

| | | | | |
|---|---|---|---|---|
| | pathway in place. Quarterly meeting to develop stronger relationships between 2 services & resolve differences in opinions on psychiatric interventions in AMHS.<br><br>No flexibility when YP in 17th year is first referred and requires long term work beyond CAMHS. | Good working relationships with adult colleagues and flexibility for YP in 17th year who require long term work beyond that which could be completed by CAMHS. | outlines escalation if disagreement occurs re: suitability of transfer.<br>Good working relationships with adult colleagues and flexibility for YP in 17th year who require long term work beyond that which could be completed by CAMHS. | |
| 3.1.3. There is a need for explicit policies regarding the process for transfer of clinical responsibility | Not achieved.<br>Protocol indicates that a quarterly transition panel will meet regarding transfer of clinical responsibility. Not operational at time of review. | Fully achieved.<br>Protocol not specific around transfer of clinical responsibility but highlights the steps in transfer and who is involved at each stage | Fully achieved.<br>Protocol outlines all roles and responsibilities in relation to transfer of care to adult services. This includes the role of consultant psychiatrist. | Partially achieved.<br>An internal proforma used to indicate transfer of consultant psychiatric responsibility, but does not have a policy to formalise implementation. |
| 3.1.4. All service users, their families and carers are introduced to and linked properly with continuing care and support services prior to moving from one form of care to another. | Partially achieved<br>Protocol indicates that CAMHS and AMH clinicians meet/ consult with YP and to agree transition. But at time of review this was not yet in place. | Substantially achieved.<br>Protocol indicates that a discussion should take place between CAMHS worker, the young person and family regarding the need to transfer. Agreement is sought at this stage. | Substantially achieved.<br>Protocol indicates that CAMHS and AMH clinicians meet to agree transition plan and consult young person. | Partially achieved<br>Informal process in place. Some evidence from staff that transitional planning takes place. Overview indicates this should happen. |
| 3.1.5. Information relevant to the risk assessment and management plan must be transferred, as should patient records and other relevant documentation, to ensure the effective exchange of information. | Partially achieved<br>Protocol does not outline how this is to be achieved. Interview with staff in validation visit suggests that all relevant information is shared and is easily accessible. | Not achieved.<br>Protocol indicates that a detailed summary is provided to adult colleagues. No specific reference to risk assessment. | Fully achieved.<br>Protocol outlines procedures for flow of documentation and exchange of information, and in line with Department's guidelines for risk assessment. | Not achieved<br>No evidence of formal or documented evidence to ensure process in place for this. Self assessment indicates efforts are made on an individual basis to ensure this is carried out. |

# APPENDIX 3: MAPPING TOOLS

## APPENDIX 3a – MAPPING TOOL FOR STATUTORY SERVICES

**IMPACT:** Improving mental health pathways and care for adolescents in transition to adult services in Northern Ireland

**Date:** _____ (day) _____(month)_____(year)

1. **Team name:** _____ **Trust:** _____

2. **Respondent:**

   Name: _____ Profession: _____ Job Title: _____

3. **Catchment population:** ……,000

4. **Service type:** CAMHS: ❑ Other specialist service (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. **Are there any trainee consultant psychiatrists in your team?** YES: ❑ NO: ❑

   If so, how many? _____

   If so, what type? ST 4-6: ❑ CT 1-3: ❑

**7. 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: _____

***(The last calendar year will be taken as January 1st – December 31st 2014)***

Number of currently open cases: _____

**8. Adult teams:** Please indicate the (statutory) adult teams your service works with on cases while you retain lead responsibility for their care in the first column and the (statutory) adult teams your service transfers lead responsibility for cases to in the second column?

| | **Retain Lead** | **Transfer** |
|---|---|---|
| CMHTs | ❑ | ❑ |
| Eating Disorders | ❑ | ❑ |
| Educational | ❑ | ❑ |
| Learning Disability: | ❑ | ❑ |
| Psychotherapy: | ❑ | ❑ |
| Primary Care: | ❑ | ❑ |
| Forensic Services: | ❑ | ❑ |
| Addiction: | ❑ | ❑ |
| Criminal Justice System: | ❑ | ❑ |
| Social Services (specify): | ❑ | ❑ |
| _____ | | |
| Others (specify): | ❑ | ❑ |
| _____ | | |

**9. Community and Voluntary Services**: Please indicate the services within the C&V sector that your services links with in the first column and transfers to young people in the second column:

| | **Retain Lead** | **Transfer** |
|---|---|---|
| _____ | ❑ | ❑ |
| _____ | ❑ | ❑ |
| _____ | ❑ | ❑ |
| _____ | ❑ | ❑ |
| _____ | ❑ | ❑ |

**10. 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:
……
……
……
……

11. **Transition numbers**: How many patients stay within the service after crossing the transition boundary?
Please state the number per year over the last three years: _____

12. **Closure policy:** Do you have a written Closure policy? If **yes,** please attach a copy. YES: ❑ NO: ❑

13. **Transition protocol:** Do you have written policy/guidelines for transition of patients under your care to adult services? If **yes,** please attach a copy.
YES: ❑ NO: ❑

**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? If **yes,** please attach a copy. YES: ❑ NO: ❑

14. **Potential referrals:** How many cases do you consider to be suitable for transfer to adult services per year?
Please state the number per year over the last three years: _____

15. **Referrals accepted:** How many cases make a transition from your service to adult services per year?
Please state the number per year over the last three years: _____

16. **Transition Process:** for patients making a transition, please indicate if the following is part of the process?

**a)** Documented hand-over planning:
YES: ❑ NO: ❑
Always: ❑
Sometimes: ❑
Never: ❑

**b)** Joint meeting with adult service:
YES: ❑ NO: ❑
Always: ❑
Sometimes: ❑
Never: ❑

**c)** Involvement of the parents/carer in care plan and decision making:
YES: ❑ NO: ❑
Always: ❑
Sometimes: ❑
Never: ❑

**d)** Involvement of the service users in care plan and decision making:

YES: ❑ NO: ❑

Always: ❑

Sometimes: ❑

Never: ❑

**e)** Preparing the young person for ending one therapeutic relationship and starting another

YES: ❑ NO: ❑

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).

YES: ❑ NO: ❑

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:

……
……
……
……
……
……

**Thank you for completing this questionnaire.**

**IMPACT Study: s.mcgrellis@ulster.ac.uk / g.leavey@ulster.ac.uk**

## APPENDIX 3b: MAPPING TOOL FOR VOLUNTARY ORGANISATIONS

**Mapping interview /questionnaire with C&V organisation that provide mental health services for young people**

1. Name of Organisation
2. Nature of Service provided, including target group, age etc.
3. Location/Address.
4. Geographical Catchment area.

5. What mental health services does your organisation provide for young people?

6. What mental health promotion work do you do with young people?

7. How is your organisation involved in the recovery of young people who experience mental ill health?

8. Does your organisation link/work in partnership with CAMH services to support young people, their parents/carers? Please give detail on the nature of this link/partnership and at what Tier this service is provided? Including practical/admin arrangements.

9. How well does this link work? What makes it work well? What are the biggest problems?

10. Does your organisation link/work in partnership with AMH services to support young people, their parents/carers? Please give detail on the nature of this partnership and at what Tier this service is provided.

11. How well does this link work? What makes it work well? What are the biggest problems?

12. What, if anything, makes it difficult to deliver your service for young people with mental health problems?

13. What would enhance the service for this group?

14. Do you have experience of supporting young people while they make the transition from CAMHS to AMHS? If yes, please give your thoughts on how well this works and what role/ contribution you make to this process.

15. Do you have experience of supporting young people who reach transition point within CAMHS (usually 18) who are discharged from services? What is your role/ contribution to their care at this time?
16. Any other thoughts or comments?

## APPENDIX 4 INTERVIEW SCHEDULES

### Appendix 4a: Focus Group Interview Schedule for Staff Teams

**IMPACT**

**IMPACT:** Improving mental health pathways and care for adolescents in transition to adult services in Northern Ireland

Funded by the R&D Division of the Public Health Agency

# Focus Group Interview Schedule for Staff Team Interviews

**Introductions and thanks**

**Format of the focus group:**

The focus group, with your permission, will be recorded and the audio will be transcribed. Only named researchers on the project will have access to the transcripts, the audio will be wiped after transcription. All transcripts will be securely stored in line with Data Protection and will be anonymised. This means that no identifying material will be used in any reports, papers or presentations produced from this study.

The interview will last no more than an hour. We will give you contact details for the project, and please do not hesitate to get in touch afterwards if you wish.

1. **FG participant Introductions**

All participants to introduce self and give a brief description of their role and responsibilities within the service.

2. **Current Transition Policies and Procedures – CAMHS to Adult Mental Health Services**

**What protocols are currently in place in your workplace with regard to the transition from CAMHS to AMHS?**

- Age when it happens and flexibility on this
- Time frame – how long does it take, when does process start
- Personnel involved within the health trust
- What is the nature of shared responsibility and exchange between CAMHS and AMHS staff in the transfer process.

- Interagency involvement – eg how much collaboration is there between statutory and other agencies and services within the community and voluntary sector? What other services are made available to the service user/ carer? How are these agencies involved in the process?
- Who takes responsibility for the process (lead professional)? How does this work in practice?
- How clear and available are the protocols for transfer made to staff? How easy are they to put in place?

**3. Management of the process – procedures.**

- What happens when a referral is being made to AMHS?
- What contact is there between CAMHS and AMHS – at what level?
- What happens if the referral is not accepted? What support is in place for SU and carer? What alternative adult provision is made for SU? Is a formal transition plan put in place?
- What happens if referral is accepted? What support is in place for SU and carer? What, if any, continuity in service is available? Warm transfer?
- What makes a positive contribution to the process?
- What makes the process difficult?
- How is case note information shared/passed between services

Service User involvement

- How are young people involved in the process, how much choice do they have, what level of options are made available to them.
- Is this standard procedure?

Carer involvement

- How are carers involved?
- Is this standard procedure?

How well are transitions supported, in terms of the resources available to staff within teams?

Can you give any examples of positive and challenging experiences in relation to resource issues.

**4. Determining and influencing factors on successful transition outcomes. Suggestions for change/improvement.**

- Eg. What impact do the different models of have on the transition outcome for a young person?
- What, from your experience, would make the transition process more successful for the young person?
- What needs to change?

**5.Site-specific question:** These will be informed by the results of the IMPACT survey and mapping.

Thank you

Give contact details for project

## APPENDIX 4b: COPY OF INDIVIDUAL INTERVIEW TOPIC GUIDE: STATUTORY SERVICES

IMPACT: Interview schedule for AMHS clinicians
Topic List: Interview Schedule for AMHS Key-workers

*Introduction*

- Thanks for agreeing to take part
- Introduce Self and role
- Reminder of aims of IMPACT project. Summarise the different stages. The overall aim of the project is to develop ideas on how to improve mental health services for young people, especially for those who may have to move from one service to another.
- Reason we want to talk to you- Client (NAME), has recently moved out of CAMHS to your service, and we are interested in the transition experience from your perspective. (We have spoken to NAME, once/twice already about his/her experience)
- Confidentiality and Permission to record interview – I would like to record the interview if you are agreeable to that. It means I don't have to write everything down, and it's a more accurate account of the interview. The audio will be transcribed but no names or identifying information will be included. We will give each interview a number and possibly a pseudonym. No one will be identifiable in any written reports. All accounts will be stored securely and the audio will be destroyed, and transcripts anonymised. All the information will be entirely confidential.

- In order to improve services, we are interested in both positive and negative feedback

- **Any questions**?

- **Consent forms** – sign

***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?**

**Thank you**

## APPENDIX 4c: COPY OF TOPIC GUIDE: SERVICE USERS

**IMPACT:** Improving mental health pathways and care for adolescents in transition to adult services in Northern Ireland

Thank you for agreeing to take part in the IMPACT project and to meet with me today. [Confirm consent.] My name is _____ and I'm a researcher at the University of Ulster. You will have had a chance to read through the information leaflet about the project. One of the main reasons for carrying out the project is to increase our understanding of the mental health services for young people and to see how they might be improved. We're particularly interested in finding out what happens when a person who is attending a child and adolescent mental health clinic has their care transferred to adult mental health services.

We would like to talk to you today about your experiences of mental health services and your experience of CAMHS. We wanted to interview you at this time, as you are coming near the end of contact with this service, and would like to talk with you again in a few months time when you have transferred to another service. This will help us to develop ideas on how to improve services, especially for people who have to move from one service to another, and for their carers.

**The interview format**

Before we begin I want to make a few key points about this session -

- The interview will last about 30-45 minutes and will be recorded – this will allow us to capture your views as best we can, and will mean I don't have to worry about writing everything down. Are you happy with that?
- The interviews will be confidential, this means that only authorised staff on the project will have access to them. 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 another person. We would discuss what to do in that case. The audio and any transcripts, on paper or on computer, will be locked away and password protected. We will also anonymise the transcripts which means we will never attach your name to the interview and will take out or change detail that could possibly identify you. Once we do this the audio recording will be wiped.
- To get permission to do this research we have to work to a very strict ethical and professional code, as set down by the University and by Health Service.

Are there any questions you want to ask before we start?

**1. Child & Adolescent Mental Health Services – illness, entry**

To begin with, it would be helpful if you could tell me about the circumstances that led to your contact with Child and Adolescent Mental Health Services in the first instance?

[***Probe:*** What was happening at the time in your life? What age were you?
*Circumstances* How would you describe what was happening to you? What symptoms did you experience? When did you first experience this problem? Who did you talk to about this problem?
Did you feel that you needed professional help at that time?

[***Probe:*** How did you come to be in contact with services?
*Care pathway* Who made the referral, to where. What happened then?

Probe: What have you been told about this problem? Do you agree with this?
What kind of help did you get from this service CAMHS?
*Suitability of service* How do you feel the service has helped you?
In your opinion has this service been right for you?
What parts of the service did you find most helpful?

What was unhelpful?
Have you experienced any difficulties with the service? Tell more
What, if anything, would have made your experience better?

**2. Communication**

How do you get on with the keyworkers and staff in CAMHS? Are there people within the staff that you don't get on with? (if yes, why?)

Probe: How easy has it been to talk about your issues and problems

*Empathy* How well do you feel they listen to you?

How well do you feel they understand what you are experiencing & feeling, and understand things from your perspective.

How often do you meet with staff? How do the meetings generally go?

How beneficial would you say they are for you?

Probe:

*Staff relationship* How would you describe your relationship with the CAMHS staff?

How much contact do you have with them?

**3. Support from Staff**

How well supported do you feel?

In what practical ways do you get support? Examples….

Probe: What else could the staff do to help [Name]

*Gaps* Is there anything that you would like or need help with, that isn't provided now?

In what ways does the service support or encourage you to help yourself?

**4. Moving on**

In the next few months it is likely that you will be moving on from this service to the adult services – how do you feel about that?

Probe: When do you think will be the right time for moving on?

What do you think needs to happen before you feel able to move on?

How much help do you think you will get at this service to make that happen?

Have the staff in CAMHS discussed the move to adult services with you (& your family)

Probe: How did that go? How helpful was it? What kinds of information did you get? (C&V)? Do you think that there are issues, which haven't been discussed? What are these?

Do you feel that your views have been fully taken into account? (Probe for disagreement )

Do you feel that you have been involved in making the decisions about your future?

Tell me about your parents and their views about what has happened? Have they been involved in making the decisions? How do you feel about that?

How well do you think you have been prepared for the move?

Have you met anyone from Adult services? How did that go?/Would you like to?

*Hopes & fears* What are your expectations/hopes about leaving this service?

What concerns, if any, do you have about leaving?

What do you think would help you move on from CAMHS?

**Thank you for taking part.** *Check contact details and consent to keep in touch, means of contact and how often. Approximate time of next interview. Give project contact details again.*

## APPENDIX 4D: INTERVIEW SCHEDULE FOR PARENT/CARER

**IMPACT:** Improving mental health pathways and care for adolescents in transition to adult services in Northern Ireland

**Introduction**

Thank you for agreeing to take part in the IMPACT project and to meet with me today. [Confirm consent.] My name is _____ and I'm a researcher at the University of Ulster. You will have had a chance to read through the information leaflet about the project. It's funded by the Public Health Agency and one of the main reasons for carrying out the project is to increase our understanding of the mental health services for young people and to see how they might be improved. We're particularly interested in finding out what happens when a person who is attending CAMHS has their care transferred to adult mental health services.

We would like to talk to you today about your own and …. [Name of Service User's] experiences of mental health services and their experience of CAMHS as they are coming near the end of contact with this service. This will help us to develop ideas on how to improve services, especially for people who have to move from one service to another and for their carers.

**The interview format**

Before we begin I want to make a few key points about this session -

- The interview will last about 30-45 minutes and will be recorded – this will allow us to capture your views as best we can, and will mean I don't have to worry about writing everything down. Are you happy with that?
- The interviews will be confidential, this means that only authorised staff on the project will have access to them. The audio and any transcripts, on paper or on computer, will be locked away and password protected. We will also anonymise the transcripts which means we will never attach your name to the interview and will take out or change detail that could possibly identify you. Once we do this the audio recording will be wiped.
- To get permission to do this research we have to work to a very strict ethical and professional code, as set down by the University and by Health Service.

Are there any questions you want to ask before we start?

**5. Child & Adolescent Mental Health Services – illness, entry**

To begin with, it would be helpful if you could tell me about the circumstances that led (NAME) to getting care from Child and Adolescent Mental Health Services?

| | |
|---|---|
| [***Probe:*** | What was happening at the time in his/her life? What age? |
| *Circumstances* | What did you think was happening to (NAME)? |
| | Did you feel that (Name) needed professional help? |
| [***Probe:*** | How did you come to be in contact with services? |
| *Care pathway* | Who made the referral, to where. How long did it take to get help? |
| | What happened then? |
| Probe: | What kind of help did you get from CAMHS |
| *Suitability of service* | How do you feel the service has helped [Name] with his problems? |
| | In your opinion has this service been right for [Name] |
| | What parts of the service did you find most helpful to you/ & N? |
| | What was unhelpful? |
| | Have you experienced any difficulties with the service? Tell more |
| | What, if anything, would have made your experience better? |

**6. Communication**

How do you get on with the key workers and staff in CAMHS

| | |
|---|---|
| Probe: | How easy has it been to talk about your issues and problems |
| *Empathy* | How well do you feel they listen to you? |
| | How well do you feel they understand what you are experiencing & feeling and understand things from your perspective. |
| | How often do you meet with staff? How do the meetings generally go? |
| | How beneficial would you say they are? |
| Probe: | |
| *Staff relationship* | How would you describe your relationship with the CAMHS staff? |
| | How much contact do you have with them? How involved are you? |

**7. Support from Staff**

How well supported do you feel?

In what practical ways do you get support? Examples….

Probe: What else could the staff do to help [Name]

*Gaps* Is there anything that you would like or need help with, that isn't provided now?

**8. Moving on**

In the next few months it is likely that [Name] will be moving on from this service to the adult services – how do you feel about that? How much have you been involved in the decision and planning process?

Probe: When do you think will be the right time for moving on?

What do you think needs to happen before [Name] is able to move on?

What contact do you have with other services – GP, voluntary groups?

Have the staff in CAMHS discussed the move to adult services with you (& your family)

Probe: How did that go? How helpful was it? What choices/options were you given?

How well do you think [Name] has been prepared for the move?

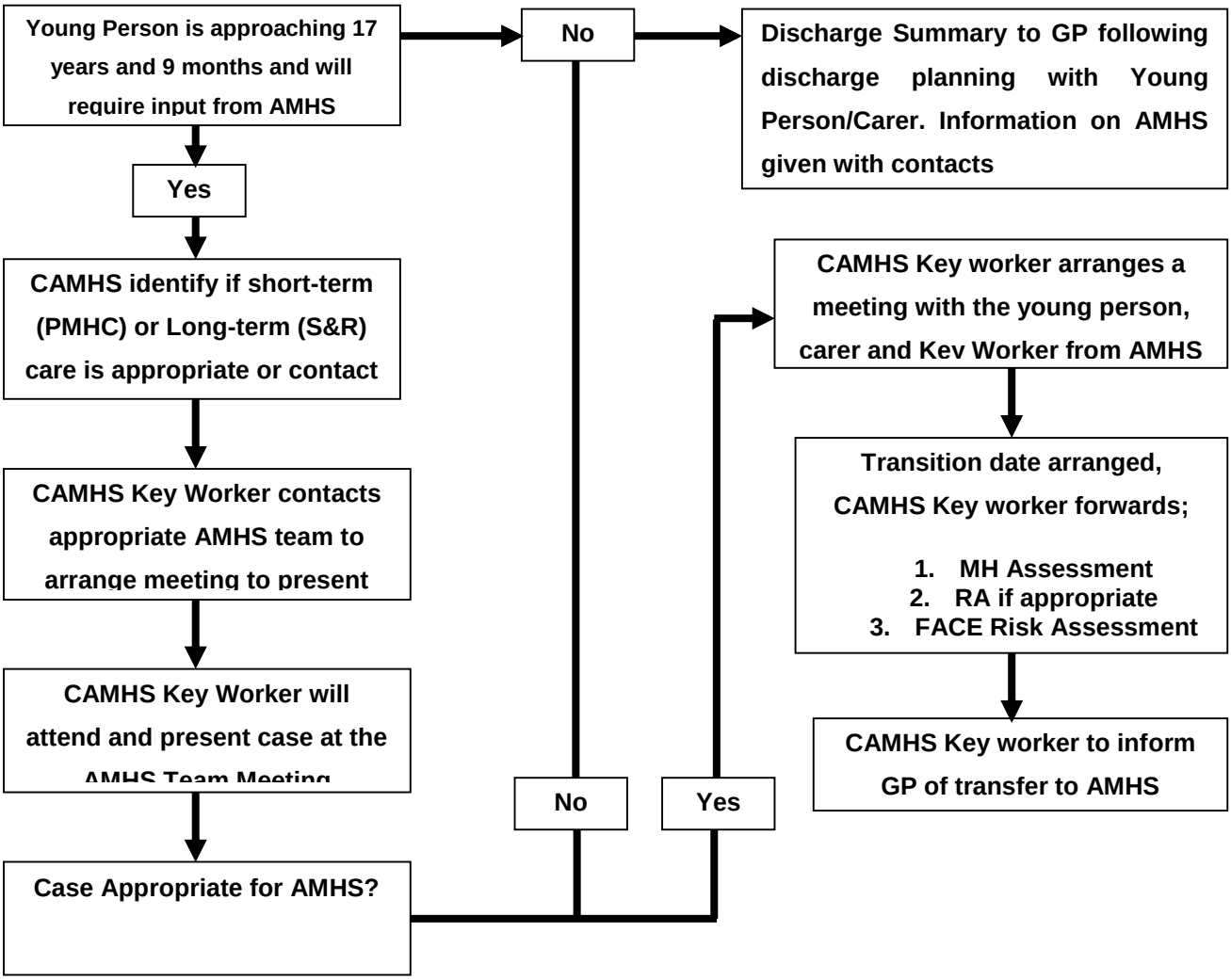
What are you hoping for [NAME] when s/he leaves CAMHS?

Anything else not covered?

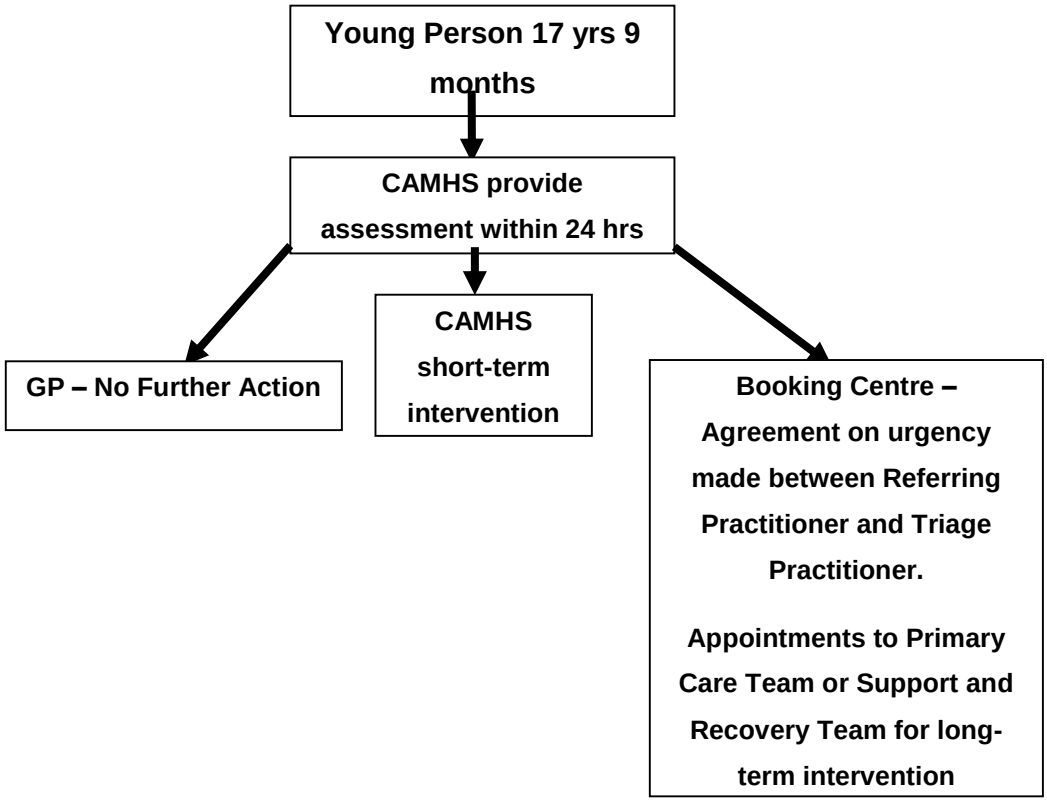
**Thank you for taking part.** *Check contact details and consent to keep in touch, means of contact and how often. Approximate time of next interview. Give researcher contact details again*.

## APPENDIX 5: TRANSITION PATHWAY YOUNG PERSON KNOWN TO CAMHS - SHSCT

(Source- Southern HSC Trust, Protocol 2016)

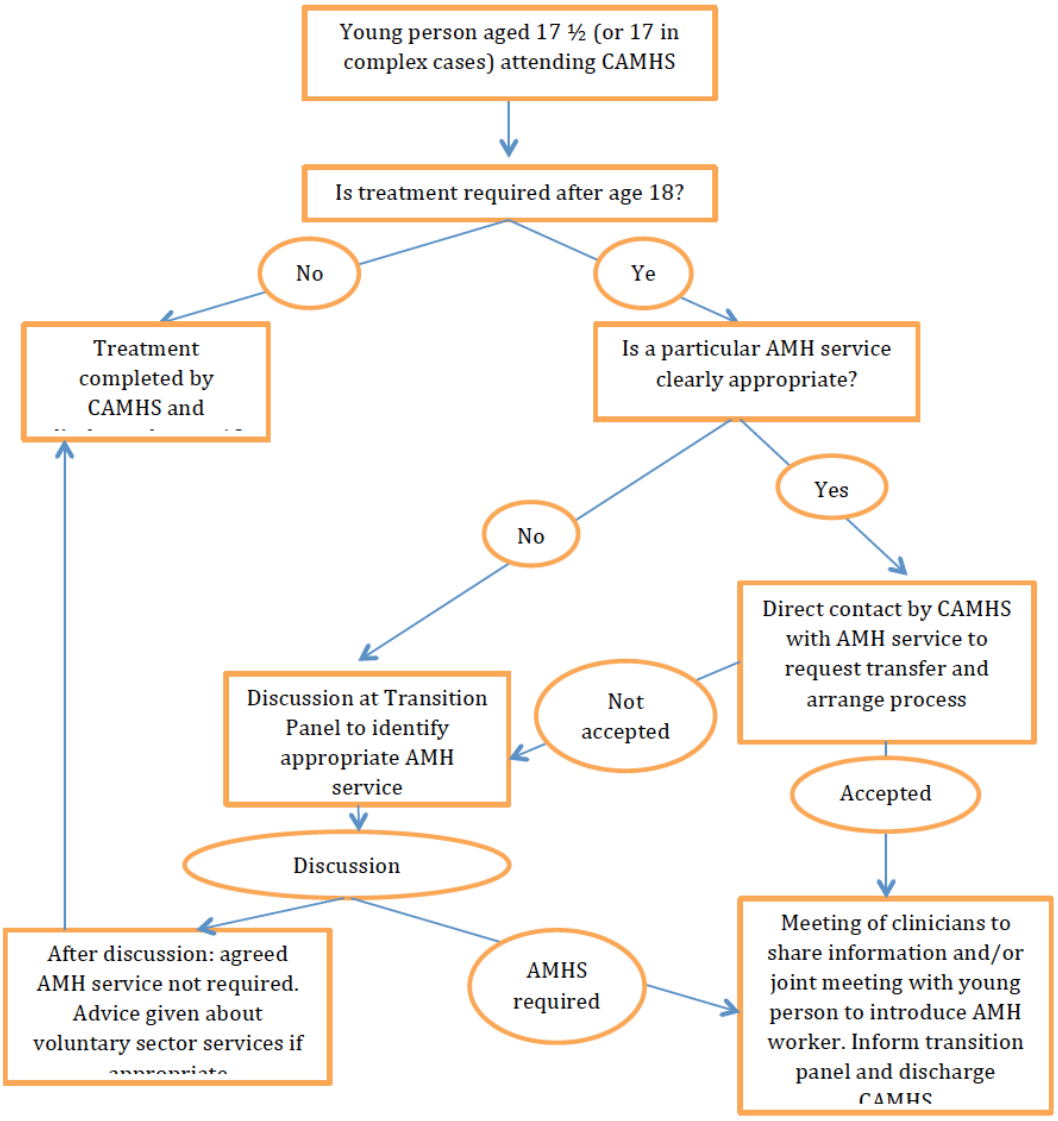


**CAMHS Liaison Referrals (Emergency) (Southern HSC Trust)**



## APPENDIX 6: TRANSITION PROTOCOL FOR WHSCT

**Flow Chart illustrating Transition Policy between CAMHS and AMHS in Western Health and Social Care Trust** (Source: Western Trust Transition Protocol)




- Many young people enter CAMHS after 17 ½ and decisions about transition are thus made much closer to their 18th birthday
- Young people with mental health needs for whom no commissioned adult service is available should be discussed at the transition panel and the gap in service provision identified and recorded.
- A few young people present in crisis near their 18th birthday but are not known to CAMHS. This requires discussion between lead clinicians in CAMHS and AMH to ensure appropriate case management on a case by case basis.

# APPENDIX 7: INVITATION & INFORMATION ABOUT STUDY

**IMPACT STUDY Participant Information Sheet**
**Improving mental health pathways and care for adolescents in transition to adult services in Northern Ireland**

**Invitation to take part**

There is a need to better understand the needs of young people and their carers throughout their contact with health and social care services. Of particular importance is the transition of young people into adult mental health services, which for a variety of reasons, can be a difficult experience for some people. In recognition of this, the Research and Development of the Public Health Agency in Northern Ireland has funded a major initiative to improve mental health services for young people. The study led by researchers at the University of Ulster and in collaboration with professionals from a range of health and social care organisations will be undertaken over three years and during this time we aim to carry out in-depth interviews with a wide range of service users, carers and professionals. Specifically we aim to examine how and why do mental health services in the Health and Social Care Trusts in NI differ in their policies and provision of care for young people in the transition to adult services? Which factors influence adolescents' engagement with services and continuity of care? We hope that the findings from this study will allow for the development of services that better reflect the needs of young people and their families.

The experience and perspective of professionals who are involved in the provision of mental health service to young people is an important part of the project. By talking with Service Users, Carers and the Professionals who work with them, we hope to build a better understanding and a more comprehensive picture of what is involved in the transition of care from CAMHS to adult services.

**What is involved?**

In addition to focus group discussions with multi-disciplinary teams designed to map the structure of CAMHS and AMHS, we would also like to speak with keyworkers of young people making the transition from CAMHS to AMHS. The interviews will last between 30 minutes and one hour. We will use a semi structured interview schedule to explore the key issues associated with transition from the perspective of the professional.

**Confidentiality and Anonymity**

All data gathered will be treated confidently. With your permission the interviews will be recorded, the audio will be wiped once a transcript has been made. No names will be attached to the transcript and all identifying detail will be anonymised. Computer and hard copies of the transcripts, and any relating data, will be stored in accordance with the Data Protection Act. Only named researchers on the project will have access to the data which will be stored in a locked cabinet, or password protected computer, in a locked room. Written reports may contain quotations from interviews but these will be carefully selected and anonymised to ensure that individuals will not be identified in any way.

Your participation is completely voluntary. If you agree to be interviewed your contact details will be forwarded to a researcher from the IMPACT team, who will get in touch with you to arrange a convenient time and place to meet.

**Further information** If you would like more information or have any questions please contact Sheena McGrellis, the Researcher on the project, at The Bamford Centre for Mental Health and Wellbeing, University of Ulster, Magee, BT48 7JL, s.mcgrellis@ulster.ac.uk, tel 028 716 75457.

**Complaints:** If you are not happy with any aspect of the study and would like to make a complaint please get in touch with Prof Gerry Leavey, Bamford Centre for Mental Health and Wellbeing, University of Ulster, Magee, BT48 7JL, g.leavey@ulster.ac.uk, tel 028 716 75245. Thank you for your time.

## APPENDIX 8 LIST OF CVS SERVICES PROVIDING SUPPORT TO SU CORE GROUP

The community and voluntary organisations the young people named were:

MACS, FASA, VOYPIC, Princes' Trust, Zest, Barnardos, React, Action Mental Health (New Horizons) NIAMH (Beacon Centre), Lifeline, Women's Aid, and a local LGBT group.

As well as the eight young people from the core interviews seven others were interviewed through VOYPIC and Action for Children, and shared their experience of both the statutory and voluntary services. Parents (not all from the core group) and keyworkers named additional third sector organisations involved in the care of young people they worked with or parented. These included, Start 360, Aware, Well Women, Extern, DAISY, Well 2 Project, The Junction, Mindwise, Extern, Praxis, Phoenix, Pavestone, Breakthru, Autism NI, Pips, and The Lighthouse.

## APPENDIX 9 RAPID EVIDENCE REVIEW SUMMARY TABLES

Table 1: Relevance Checks & Quality Assessment of Reviews

| Area | Author, Year, Country | Search Strategy? | Comprehensive search? | Relevance checks? | Quality assessment procedures? | Findings individual studies presented? | Adequate data to support review findings? | Clear Recommendations Policy/practice? | Score Commentary |
|---|---|---|---|---|---|---|---|---|---|
| Mental Health (SED) CAMHS to AMHS | Davis (2003) | No | No | No | No | Some within body of text | No | Yes but insufficient detail provided on individual studies | 1/7 This is a discussion paper rather than evidence review. |
| **Mental Health** CAMHS to AMHS | **DiRezze et al (2015) Canada** | **Yes** | **Yes** | **Yes** | **Yes** | **Yes** | **Yes** | **Not all focused on mental health** | **Focus on developmental transitions – not all with focus on mental health** |
| **Mental Health** | **Embrett et al (2015) Canada** | **Yes** | **Yes** | **Yes** | **Yes** | **Yes** | **Yes** | **Yes** | **7/7 Focus on outcome studies** |
| **Mental Health** | **Paul et al (2014) UK** | **Yes** | **Yes** | **Yes** | **Yes** | **Yes** | **Yes** | **Yes** | **7/7 Strong review** |
| **Mental Health** | **Mulvale et al (2016)** | **Yes** | **Yes** | **Yes** | **Some** | **Some detail** | **Yes** | **Yes** | **7/7 Strong review focus on care philosophy** |
| Mental health | Munoz-Solomando et al. (2010) | No | No | No | No | In narrative form | Yes | | 1/7 Include as background review |
| Mental Health | Murcott et al (2014) | No | No | No | No | No | No | Yes | 1/7 Include as background review |
| **Mental health** | **Reale & Bonati (2015) Italy** | **Yes** | **Yes** | **Yes** | **Yes** | **Yes** | **Yes** | **Yes** | **7/7 Excellent review** |

| Area | Author, Year, Country | Search Strategy? | Comprehensive search? | Relevance checks? | Quality assessment procedures? | Findings individual studies presented? | Adequate data to support review findings? | Clear Recommendations Policy/practice? | Score Commentary |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | | **Include in overview** |
| Mental health | Sukhera et al (2015) Canada | Yes | No | No | No | No | Yes | Yes | 2/7 Poor quality include as background information |
| Mental Health | Ubido and Scott Samuel (2015) UK | Yes | Yes (but limited in detail) | No | No | Yes Some but not in table format | Yes | Yes | 5/7 Moderate quality review |
| Young people transitioning from children's to adult health and social services | NICE (2014) UK | Yes | Yes | Yes | Yes | Yes | Yes | Yes | 7/7 Use as core study |
| Young people leaving care | Christian and Schwartz (2013) USA | No | No | No | No | No | No | No – very limited recommendations for transition from CAMHS to AMHS | 0/7 Exclude from synthesis but include as background |
| Young people in care | Akister et al (2010) UK | No | No | No | No | Some data in separate pdf | Yes | Some but insufficient data presented on transition experience | 1/7 Exclude from synthesis but include in background |
| ADHD | Young et al (2011) UK | No | No | No | No | No | No | Yes but insufficient evidence presented | 1/7 Weak review Exclude from synthesis but include as background |

| Area | Author, Year, Country | Search Strategy? | Comprehensive search? | Relevance checks? | Quality assessment procedures? | Findings individual studies presented? | Adequate data to support review findings? | Clear Recommendations Policy/practice? | Score Commentary |
|---|---|---|---|---|---|---|---|---|---|
| Eating Disorders (Anorexia Nervosa) | Winston et al 2012 UK | Yes | No | No | No | Not in tabular format | Insufficient detail provided | Yes | 2/7 Exclude from review as insufficient information provided on included studies. Use as background. |
| **Excluded Reviews** | | | | | | | | | |
| Mental Health | Anderson (2006) HASCAS Tools for Transition | No | No. | No | No | No (Annotated bibliography to support the review was no longer available on the link given.) | No | No | 0/7 Exclude Good background on key policies in England |
| Mental Health | Kim et al (2012) USA | Yes | Yes | Yes | No | Yes | Yes | Yes | 6/7 Exclude not focused on transitions |
| Chronic illness including ASD Models of transition | Watson et al 2011 | Yes | Yes | No | No | No Only in narrative format | No | Yes but insufficient evidence presented | 3/7 Focus on chronic conditions but included search for ASD. No models identified. |
| General healthcare | Crowley et al (2011) | Yes | Yes | Yes | Yes | No | Yes | Yes | 6/7 |

| Area | Author, Year, Country | Search Strategy? | Comprehensive search? | Relevance checks? | Quality assessment procedures? | Findings individual studies presented? | Adequate data to support review findings? | Clear Recommendations Policy/practice? | Score Commentary |
|---|---|---|---|---|---|---|---|---|---|
| Chronic illness | | | | | | | | | Exclude from overview as search did not identify any mental health intervention. Good summary of rationale for different interventions (e.g. Patient aspects, staff aspects, service aspects) |
| General healthcare Developmentally appropriate healthcare (DAH) | Farre et al (2015) England | Yes | Yes | No | No | Yes | Yes | Yes | 5/7 But not focused on mental health. Exclude from overview but include in background on DAH |
| Mental Health General mental health of young people | Patel et al 2007 England | Yes | No | No | No | Not in tabular format | No | No | 1/7 Focus on mental health of young people – not specifically on transitions. Describes some models of care e.g. Headspace |

Table 2: Summary of included high quality reviews

| Author (year) Country | Population | Type of review | No. Included studies | Focus | Included in? Quality assessment | Findings |
|---|---|---|---|---|---|---|
| Embrett et al (2016) Canada | Young people with mental health problems transitioning between CAMHS and AMHS | Systematic review | **7 studies**<br><br>3 Quantitative<br>1 Qualitative study<br>2 Mixed methods | To conduct a SR of the evidence that evaluates existing health system services addressing the transition between CAMHS and AMHS | Reviewed by DF<br>***<br>7/7 | Findings suggest little data exist on the effectiveness of transition services/programmes. While the available evidence supports meetings between youth and youth caseworkers prior to transitions occurring, this is not common practice. Barriers to effective transitions were categorized as logistical (ineffective system communication), organisational (negative incentives), and related to clinical governance |
| Paul et al (2014) England | Young people with mental health problems transitioning from CAMHS and AMHS<br><br>Staff<br><br>Families | Systematic Review | **19 studies**<br><br>3 intervention studies<br>2 study of YP/Parents/SP<br>3 studies of parents<br>2 studies of YP<br>7 studies of SP<br>1 casenote review<br>1 secondary analysis | To systematically review:<br>1. Effectiveness of different models of CAMHS to AMHS transitional care<br><br>2. Service users and staff perspectives<br><br>3. Facilitators and barriers to effective transition | NICE (2016)<br><br>Good<br>++/++<br><br>DF<br>***<br>7/7 | High quality evidence of transitional care is lacking.<br>Data generally support the development of programmes that address the broader needs of young adults & their mental health needs, but further evaluation required.<br>Developing robust transitional mental health care will require the policy-practice gap to be addressed and the development of acceptable, accessible, responsive and age-appropriate provision. |
| Mulvale et al (2016 | Young people with mental health problems transitioning from CAMHS to AMHS | Systematic review | **12 studies**<br><br>Not all primary research projects – some discussion papers but on theme of care culture | To review literature about CAMHS and AMHS care philosophies and their influence on transitions. | DF<br>High quality<br>7/7 | The studies included in this systematic review consistently report distinct philosophical differences between CAMHS and AMHS with respect to how the challenges the youth is facing are understood, the importance of family and social context, and where the balance lies in the need to protect versus expect responsibility of youth. |

| | | | | | | |
|---|---|---|---|---|---|---|
| Real & Bonati (2015) | Young people with mental health problems transitioning from CAMHS to AMHS | Systematic review | 33 studies<br><br>17 on mental illness<br>7ADHD<br>3 eating disorder<br>2 SED<br>1 ASD<br>4 Learning disability | To summarise recent evidence on the transition from child to adult mental health services | DF<br><br>High quality<br>7/7 | The review found the need for longitudinal, controlled studies to identify and evaluate optimal service models (including seamless transition protocols) for young people transitioning from AMHS to CAMHS. |
| NICE (2016) | Young people transitioning from children's services to adult services | NICE guidance | 3 studies with relevance to mental health | Transition from children's services health and social care | High quality<br>7/7 | Only three studies relevant to transitions and mental health |

**Table 3: Studies Exploring Experience of Transitions from Children's Services to Adult Services**

| Author (year) Country | Population | Focus of Research | Design Sample size | Findings | Included in review and quality assessment score |
|---|---|---|---|---|---|
| **Mental illness** | | | | | |
| Day et al. (2007) England Sheffield | Young people Parents Service providers | To examine, in detail, the transition arrangements of young people with acute mental health problems | Mixed methods Focus groups with YP (1 group n=3), interviews with: YP (n=3), parents n=6, GPs n=2, keyworkers n=5. | This study explored the experiences of 13 young people at different stages in the transition process from the perspectives of yp (all female), parents, service providers. The study found that some young people found some of CAMHS not to be appropriate to their developmental stage (some methods employed perceived to be 'child-like' but adult services were viewed to be 'scary' by some. | Reviewed by team.(Included in NICE 2016 but findings not provided). Moderate quality 28/36 Very small samples (6 young people) |
| Gilmer, Ojeda et al (2012) USA | Young people attending youth specific programmes, their parents & service providers | To assess the needs of for mental health and others services among transition age young people attending youth specific programmes | Focus groups 13 focus groups using purposive sampling YP aged 18-24 8 groups n=74 Parents 2 groups n=14 SP 3 groups n=14 | • YP wanted improved scheduling of appointments, shorter waiting times, improved patient provider relationship, group therapies, and programmes that provide skills to develop nurturing relationships (Duration and frequency of appointments acted as a barrier to establish rapport)<br>• P/C & SP wanted more community based and peer led services<br>• YP/PC/SP all wanted more housing options and mentors with similar life experiences to serve as role models & provide social support for young people<br>• All wanted a service that fostered independence | Reviewed by team Good quality 32/36 |
| Hovish, Weaver, Islam, Paul, and Singh (2012) UK Track | CAMHS service users and their parents, and clinicians for both CAMHS and AMHS | To understand the experiences of Young people, their parents and CAMHS/ AMHS clinicians of transition between CAMHS and AMHS | Semi structured interviews and thematic analysis of multi-perspective case study documents. Young people (n=11) CAMHS | • Service provider wanted more flexibility rather than strict age cut off.<br>• AMHS do not contact family/parents, which was appreciated by some, however others felt isolation<br>• Parents reported less involvement in youth's care after 'abrupt' transition to the AMHS, and wanted more time in CAMHS | Paul et al (2014) Score 31/36 Reale and Bonati (2015) Quality score 10 Embrett et al (2015) |

| Author (year) Country | Population | Focus of Research | Design Sample size | Findings | Included in review and quality assessment score |
|---|---|---|---|---|---|
| | | | service users, parents (n=6) CAMHS clinicians (n=6) and AMHS clinicians (n=3) | • Time was a barrier for service providers<br>• No party was satisfied with the current system and felt there was substantial room for improvement in order to provide better care to the youth<br>Facilitators to transition<br>• Meetings between caseworkers and youth before beginning treatment were important to establish a relationship.<br>Recommendations for improvement of transition<br>• Continuity of care between youth and established caseworkers during the transition period<br>• Clinicians believed more 'joint working' between CAMHS and AMHS were needed to ensure better transition<br>• Transfer planning meetings and parallel care were valued by YP, parents, and clinicians<br>• Gradual preparation, transition planning meetings, periods of parallel care and consistency of keyworker promoted positive experiences of transition. | Quality score (0.6) |
| Jivanjee and Kruzich (2011) USA | Young people aged 17–23 years (mean 19.4), with mental health difficulties, and their parents | To explore young people's and their parents' experiences of mental health services and family/peer support | Qualitative study – focus group (8 with parents and 12 with young people) and comparative analysis.<br>16 young people (aged 17-23 – average age 19.4) and 18 parents | • Parents and young people both appreciated wrap-around services.<br>• Parents valued practical support and communication, highlighting the difficulties caused by restrictive eligibility criteria and loss of services after age 18.<br>• Young people emphasised the difficulties of finding and accessing age-appropriate services and support. | |
| RIQA (2011) Northern Ireland | Young people with mental illness and their parents | | Consultation using self completion survey with n=64 young people and | As this consultation was part of a review of CAMHS, only limited detail is provided on the young people's experience of transition. Seven young people stated that the move had been positive. Some experienced joint-working between CAMHS and AMHS. | Not possible to fully assess quality as findings |

| Author (year) Country | Population | Focus of Research | Design Sample size | Findings | Included in review and quality assessment score |
|---|---|---|---|---|---|
| | | | n=41 parents of children with experience of CAMHS. 8 young people had experienced adult services, and 2 were in the process. | Three of the young people reported a negative experience of the transition: one did not receive any support during the transition and another commented that as the transition was to a service in England they received little support. One young person, who was still in the transition process, stated that they felt unsupported and did not know what was happening in relation to their plan. Five young people met with a professional from adult mental health services in advance of their transition and found this extremely helpful. Some of the young people who moved to adult services described it as a scary and distressing experience. Only 2 parents had experience of the transition, and were happy with the experience. | reported within review of CAMHS. |
| Backman et al (in prep) USA | Young people attending YTP or Intensive Case Management programmes | To explore the challenges young people experience during the transition from CAMHS to AMHS | Interviews (n=38) Focus group (1 comprising of 9 young people( | • Whilst most YP reported being informed about the transition several months before the transition, some reported that they had not been informed that they would 'age out' of the service.<br>• YP would like to have more written information on the process, what's offered, and how to access it, and how adult services differ from CAMHS.<br>• Some young people appreciated having their parents involved in the process<br>• The availability of AMHS was a noted concern for many participants. Many young people were on a waitlist of upwards to one to two years to access services<br>• Geographic location was difficult for some from more rural outlying areas. (Adult service was 'you come to us not we come to you).<br>• AMHS not perceived as meeting their developmental needs.<br>• Some YP saw the transition to AMHS as an opportunity for personal growth. | Paper received from Mario Cappelli<br><br>Reviewed by team<br>Score 26/36 |
| Burnham Riosa et al (2015) Canada | Young people preparing to transition from | To investigate the lived experiences of late adolescents | In-depth interviews with n=10 participants | Findings<br>• YP did not appear ready for an institutional transition. | Reviewed by team<br>Score 30/36 |

| Author (year) Country | Population | Focus of Research | Design Sample size | Findings | Included in review and quality assessment score |
|---|---|---|---|---|---|
| | CAMHS to AMHS. | who may be transitioning into adult mental health services | recruited from an outpatients CAMHS clinic. Mean age of participants = 17.41 years. | • Fears of uncertainty and not knowing about adult services contributed to the overall experience of transition.<br>• YP expressed a desire to be actively involved in the possible service transition.<br>• Young people want transition to be gradual; to be informed of the details of the transition process and the adult services; and for there to be maintained, open communication between child and adult mental health clinicians throughout the transition process.<br>Recommendations<br>• YP need support for the transition to adulthood as well as transition to adult services.<br>• Formal services for late adolescents that are guided by both child and adult clinicians may be helpful in assisting young people and their families for the transition to adulthood and adult services. | |
| Klotnick et al (2014) USA | Young people (n=29) with mental illness before and after the transition. Age 18-25 | To explore young people's experiences of the two service before and after the transition | Qualitative interviews | Descriptions of adult services were vague and superficial in comparison to the lengthy descriptions provided for child service, (i.e. job searches, and the relationship with clinician) | Paul et al (2014) Score 25/36 |
| Lindgren et al., (2015) Sweden | Young people with mental illness | To explore young adults' experiences of psychiatric care during transition to adulthood | Interviews with n=11 young people (7 females and 4 males) aged between 19 and 26 years. | • YP experienced both supportive and unsupportive relationships<br>• Poor support from professionals throughout the transition process led to feelings of hopelessness and increased the risk of disengagement from services.<br>• Young people placed value on the therapeutic relationship to empower them to feel independent in their care and other areas of their life.<br>Recommendations | Reviewed by team Score 25/36 |

| Author (year) Country | Population | Focus of Research | Design Sample size | Findings | Included in review and quality assessment score |
|---|---|---|---|---|---|
| | | | | • Support during the process of transition is essential for a successful transition to secure ongoing engagement with services<br>• To support recovery, services need to facilitate the personal development of YP and provide access to social support. | |
| McGrandles and McMahon (2012) UK | Young person with eating disorder & mental health issues | To explore key issues in relation to the transition from CAMHS and AMHS | Literature review (no details provided) combined with a case study of a young person with an eating disorder as she transitions out from CAMHS | The key findings relate to the review of the literature:<br>• Transition is often seen as unsatisfactory<br>• Poor transition may result in YP disengaging from services<br>• Transition should be approached with flexibility, carefully aligned to the YP's developmental stage with appropriate service provision<br>• All services and staff should work collaboratively with YP and carers<br>• Nurses have a central role in supporting YP and their carers during the transition and ensuring continuity between services | Reviewed by team<br>Score 18/36<br><br>Presents a case study to illustrate key points from literature review<br>Poor description of the methodology |
| Wheatley et al (2013) UK | Young people transitioning out of inpatient CAMHS to inpatient AMHS | To gain a fuller account of the experience of young people during transition from secure adolescent mental health services to secure adult mental health services and to add to the knowledge around the transitional process. | Qualitative interviews with n=8 young women who transitioned from medium to secure inpatient service to medium to low adult service. All detained under the Mental Health Act (1983).<br><br>Content analysis | Themes included:<br>• the negative impact of aggression from other patients,<br>• the importance of relationships with staff and other patients,<br>• the need for informed involvement in all aspects of the transition process.<br><br>An increase in positive statements regarding the post-transition experience suggests that moves have been positive although this could be explained by admission to settings of lower security.<br><br>Recommendations point to the importance of moving beyond procedural issues of transition to a focus on the social and culture gaps that appear to divide CAMHS and AMHS. | Score 28/36 |

| Author (year) Country | Population | Focus of Research | Design Sample size | Findings | Included in review and quality assessment score |
|---|---|---|---|---|---|
| | | | | • involvement in the transition process<br>• preparatory visits to adult service<br>• early introduction to adult service staff and<br>• peer buddy systems may help to alleviate anxieties regarding the move to adult services. | |
| Davis and Butler (2002) USA | Parents of children with Severe Emotional or behavioural Difficulties (SED) | To ascertain parents' views of the quality of the general transition support their child received | Survey of n=115 parents (who were members of the Federation of Families for Children's Mental Health) of children aged 16-25 with SED | • Few parents reported service systems to be helpful during transitions.<br>• Stigma prevented YP engaging with services.<br>• AMHS (generally serving an older chronically unwell clientele) did not address the specific needs of YP – e.g. housing, employment, or include parents.<br>• Parents highlighted the importance of peer advocacy support.<br>• There is a need for age appropriate services | Paul et al (2014) Score 25/36 |
| Gerten et al (2014) USA | Parents recruited from the National Alliance for Mental Health | To explore mothers' perspectives of transitional age (18–25) youths with mental disorders | Self completion survey of 19 parents of children with mental illness | Services' providers did not<br>• meet youth's needs for emotional support, preparing for independent living, practical advice,<br>• provide information on their illness<br>Services need to be more collaborative and provide case planning | Reale and Bonati (2015) |
| Jivanjee, Kruzich, and Gordon (2009) USA | Family members supporting their children with mental health difficulties in the transition. | To examine family perspectives on the transition, especially on the issue of community integration | Qualitative study using participatory methods involving researchers who had been service users and carers) Focus groups. Thematic analysis n= 42 | Parents<br>• wanted their child to be better integrated into the community and felt there was a lack of community resources to meet their needs<br>• worried about their lack of preparedness for adulthood.<br>• felt the transition was started too late. | Paul et al (2014) Score 31/36 |

| Author (year) Country | Population | Focus of Research | Design Sample size | Findings | Included in review and quality assessment score |
|---|---|---|---|---|---|
| | | | family members (in eight groups) of young people, aged 16–24 years using mental health services. | | |
| Woodward et al (2011)<br>USA | Parents of children with mental illness | To assess the health, functional characteristics, and health care service needs of young adults | Survey of parents (n=63) of children (aged 11-22) transitioning into adult services. Parents were recruited through specialist transition services for children with childhood conditions | Transition programmes should assess patient health characteristics and service needs to design effective patient-centred services<br>• Services need to be person centred | Reale and Bonati (2015) |
| **Service Providers** | | | | | |
| Belling et al (2014)<br>Track<br>UK | Health and social care workers working in CAMHs or AMHS | To investigate the organisational factors that impede or facilitate transition of YP from CAMHS to AMHS | Semi-structured interviews with n=34 staff working in CAMHS (n=16), AMHS (n=11), CAMHS & AMHS (n=3), Vol sector (n=4) | Two key themes emerged:<br>Eligibility issues<br>• Lack of clarity on service availability and eligibility criteria<br>• Different thresholds between CAMHS and AMHS<br>• Adult services not accepting under patients until 17th or 18th birthday<br>• Variability in service cut-off ages<br>Resources<br>• Adult service high case workloads – adequate staffing (EI teams reported smaller caseloads that CMHTS) & lengthy wait times which led to rigid interpretation of eligibility criteria | Reviewed by team<br>Score 36/36 |

| Author (year) Country | Population | Focus of Research | Design Sample size | Findings | Included in review and quality assessment score |
|---|---|---|---|---|---|
| | | | | • Adult services not meeting needs beyond severe & enduring mental illness (i.e. not able to meet demand for services for YP with emotional difficulties and emerging personality disorder)<br>• Services for YP with learning disability/ADHD/ASD were identified as having resource gap (this was viewed by staff from voluntary sector as a growing area of demand)<br>o Need to provide AMHS staff with skills and confidence on support YP with LD/ADHD/ASD<br>o Need for more input from primary care or outreach services | |
| Davis, Geller and Hunt (2006) USA | Child and adult mental health administrators from 41 states | To describe the nature of state services available to support the transition from child to adult mental health services | Semi structured interviews with state health administrators for both adult and child mental health. Answers used to produce descriptive statistics | A quarter of child state mental health systems and half of adult state mental health systems offered no support for the transition between child-adult services. | Paul et al (2014) Score 28/36 |
| Davis and Sondheimer (2005) USA | Members of the Children, Youth and Families Division of the National Association of State Mental Health Programme | To describe the state transition services available to youths with severe emotional and behavioural disorders, the efforts to address transitional needs, and to identify the populations eligible for CAMHS and AMHS. | n=50 semi-structured interviews<br><br>(1 member from 50 states) | Similar findings to Davis, Geller and Hunt (2006), quarter of state CAMHS, and half of state AMHS did not provide transitional support. Those states that did provide transition services only provided one service. Highlighted the need to expand CAMHS and AMHS to provide improved transition services. | Paul et al (2014) Score 22/36 |

| Author (year) Country | Population | Focus of Research | Design Sample size | Findings | Included in review and quality assessment score |
|---|---|---|---|---|---|
| Lindgren et al (2013) Sweden | Clinicians working in CAMHS and AMHS | To describe professionals' views of the transition process from child to adult psychiatry | Focus groups n=3<br><br>Nurse n=12<br>Psychotherapist n=1<br><br>Psychiatrist n=1<br>Heads of unit n=2<br>OT n= 1<br>Psychologist n=1<br>Welfare officers n= 3<br><br>Social educators n=2<br><br>Content analysis | • Child and adult psychiatry had different care cultures towards family vs individual-care<br>• Gaps might occur due to<br>○ different perspectives,<br>○ lack of knowledge,<br>○ a mutual understanding, and cooperation. | Reale and Bonati (2015) 8 |
| McLaren et al (2013) England | Health and social care professionals working with young people with mental illness | To identify the organisational factors which facilitate or impede transition to adult services<br>Identify organisational barriers and facilitators to transition | Interviews with n=34 health and social care professionals.<br><br>CAMHS n = 16<br><br>AMHS n = 11<br>CAMHS & AMHS= n= 3 Voluntary Sector = 4 | Barriers<br>• Different cultural approaches to delivery<br>• CAMHS was seen as more holistic, AMHS viewed as crisis prevention, less engagement with family<br>• CAMHS staff (& AMHS managers) unsure of AMHS ability to manage young people's development<br>• Lack of two-way communication between services<br>• Different approaches to record keeping and care planning<br>• Lack of prior experience working in other service area<br>Facilitators<br>• There are some positive approaches to collaborative working across services and agencies | Reale and Bonati (2015) 12<br>Embrett et al (2015) 0.75 |

| Author (year) Country | Population | Focus of Research | Design Sample size | Findings | Included in review and quality assessment score |
|---|---|---|---|---|---|
| | | | | ○ involving joint posts, parallel working, shared clinics and joint meetings | |
| McNamara N, Nicholas F, Ford T et al. (2013) Ireland ITRACK | Clinicians working within CAMHS and AMHS | To obtain information on annual transition numbers and existing transition policies | Structured interviews with n=57 consultant psychiatrists (32 CAMHS and 25 AMHS) | • The number of young people suitable for transfer was higher than the number of those who actually transferred to adult services<br>• lack of transition policies,<br>• lack of standardized practice<br>• poor interaction between services | Reale and Bonati (2015) 10 |
| Richards and Vostanis (2004) UK | 39 managers and practitioners from mental health, social care, education and voluntary agencies. | To establish themes of mental health needs for young people aged 16-19 years old (as perceived by their care professionals) | Qualitative study - semi-structured interviews and thematic content analysis based on grounded theory. n=39 care professionals | • Older adolescents (age 16-19) have multi-faceted needs that were not being met by current services<br>• communication between services was variable, with no formal transition between CAMHS and AMHS. | Paul et al (2014) Score 31/36 |
| **ASD, ADHD and Learning Disability** | | | | | |
| **ADHD** | | | | | |
| Swift et al (2013) UK | Young people with ADHD | To explore the experiences of young people with ADHD during the transition to AMHS | Individual interviews n=10 age 17-18 | • Timely preparation and joint-working<br>• Good clinician relationships<br>• Parental support serve to facilitate the process of transition for young people with ADHD<br>• Transitions were more difficult when ADHD was viewed as the main or sole clinical problem. Further exploration of young people's experiences of transition, and their engagement with and experience of adult services is required to provide an overall picture of facilitators to successful transition and integration into adult services. | Reale and Bonati (2015) Score 10 |

| Author (year) Country | Population | Focus of Research | Design Sample size | Findings | Included in review and quality assessment score |
|---|---|---|---|---|---|
| | | | | | |
| Hall et al (2013) England | Clinician teams working in Mental Health Services and Community Paediatric Services | To examine the provision of services and the transition process for ADHD patients | Survey of clinicians (n=96) | • Findings indicate lack of structured guidelines and limited communication between child and adult services as main barriers. Adult services often feel ill-prepared to deal with ADHD | Re ale and Bonati (2015) Quality score 11 |
| Marcer, Finlay, and Baverstock (2008) UK | Community paediatricians | To find out about the experiences of community paediatricians when transferring patients with ADHD to adult care | Quantitative (questionnaire survey)<br><br>n=78 community paediatricians | Gaps in services – only one fifth of respondents were aware of dedicated local adult ADHD clinics even though 90% thought they were needed.<br>40% of community paediatricians felt their patients with ADHD would need continuing care into adulthood, | Paul et al (2014) Score 24/36 |
| Reale et al (2014) Italy | Clinicians working with in Regional ADHD Paediatric Centres (RAPC) | To investigate the care continuity from child to adult mental services for young adults with ADHD | Survey of n=52 clinicians working with young people with ADHD aged 19-21 | • 70% of patients who turned 18 were monitored by the general practitioner.<br><br>• One fifth of patients continued to use mental health services, the majority was still monitored by the RAPC | Reale and Bonati (2015) Quality score 11 |
| **Young People with Eating Disorders** | | | | | |
| Dimitropoulos G et al (2013) Canada | Young people with eating disorder | To evaluate experiences of patients with eating disorders who had transferred to adult services | n=15 young females aged between 18-21, all had transferred from a specialised paediatric eating disorders service to an adult eating disorder service.<br>12 had Anorexia Nervosa,<br>3 had Bulimia Nervosa. | • Young people advocated for better co-ordination and communication between paediatric and adult providers to bridge the gap between the services<br><br>• Importance of adult providers increasing their knowledge about eating disorders and how to balance the young person's need for independence versus ongoing service involvement in supporting behavioural change.<br>Recommendations to improve the transfer of care.<br><br>○ developmental stage rather than age should determine readiness for transition;<br><br>○ options for 'adult treatment' should be discussed prior to transfer; | Reale and Bonati (2015) Quality score 9 |

| Author (year) Country | Population | Focus of Research | Design Sample size | Findings | Included in review and quality assessment score |
|---|---|---|---|---|---|
| | | | | ○ children's services should provide young people with opportunities to develop practical skills to manage their care independently | |
| Dimitropoulos G et al (2012) Canada | Clinicians working with young people with eating disorders in paediatric and adult services | To evaluate clinicians' perspectives on the service transition process for eating disorders | 2 focus groups Focus group 1 (Paediatric services n=7 participants including a transition worker, youth worker, 2 social workers, 2 nurses and 2 paediatricians) Focus group 2: (Adult services) n=10 participants including 2 dieticians, 4 nurses, 2 social workers, 1 OT and 1 psychiatrist. | • Clinical factors associated with eating disorders may interfere with a successful transition<br>• The influence of the illness on denial of the condition, and on recovery<br>○ Acts as a barrier to preparing for adult services<br>○ Impacts on willingness to engage in treatment<br>• The effect of the illness on normal developmental processes<br>• The decline of parental involvement | Reale and Bonati (2015) Quality score 9 |
| **Young people with Learning disability** | | | | | |
| Kaehne et al (2011) Wales | Health professionals working in CAMHS or AMHS | To explore partnership working in the transition from CAMHS to AMHS for young people with a learning disability | Interviews with mental health professionals (n=8) working in 3 health authorities 5 involved in frontline services and 3 in strategic planning | Only a small number of young people with learning disability transitioning from CAMHS to AMHS.<br>Engagement with young people with LD was often brief. (YP transferred to CAMHS when transition to AMHS was imminent)<br><br>Mental health services in all 3 areas were not integrated into the health and social care teams which meant there was a potential 'triple rift' in service linkage: between CAMHS and AMHS, between mental health services and secondary and primary services, and between mental health services and adult social care.<br>Closer co-operation between care services and mental health services was required. | Nice guidelines (2016) +/+ |

| Author (year) Country | Population | Focus of Research | Design Sample size | Findings | Included in review and quality assessment score |
|---|---|---|---|---|---|
| | | | | • Poor information exchange due to lack of appropriate systems.<br>• Lack of knowledge about eligibility criteria<br>• CAMHS staff limited knowledge of what is available in AMHS<br>• Need for joint planning meetings | |

Table 4: Studies reporting Case Note Reviews and Secondary Analysis of Databases

| Author (year) Country | Population | Focus of Research | Design Sample size | Findings | Included in review & quality assessment score |
|---|---|---|---|---|---|
| Mental Health | | | | | |
| Arcelus et al (2008)<br>UK | Young people with **eating disorders** transition from CAMHS and other services | To compare the transitions of YP with eating disorders from CAMHS and from other services | Review of case notes of all YP referred to a specialist Adult Eating Disorder Service (AEDS) over a 4 year period<br>N=209 aged between 16 and 25 years. | • Approx 30% of patients continue to require care in adulthood but only a small number were referred to AMHS by CAMHS<br>○ 149 (7.8%) were referred to AEDS or AMHS by their GP, 32 (15.5%) were referred by CAMHS, and the remainder by another specialist service (e.g. Adult psychiatry)<br>• 57 (27.7%) had previous involvement with CAMHS from which 33 (57.9%) had inpatient treatment<br>• YP with previous involvement with CAMHS presented with lower self-esteem and maturity fears than those without previous involvement<br>• Study highlights the importance of robust transitional arrangements, and need to look at issues such as self-esteem and maturity of the YP who are transitioning. | Reale and Bonati (2015)<br>Quality score 11<br><br>Winston et al (2012)<br>No quality assessment |
| George et al (?)<br>Conference paper<br>England<br>Walsall | Young people transitioning from CAMHS to AMHS | To determine the compliance with trust guidelines on the transfer from CAMHS to AMHS | Review of case notes of all YP transferring from CAMHS to AMHS in Trust<br>N=12 | • All cases had detailed referral letter<br>• 8 / 12 had a care co-ordinator in AMH allocated with 2-3 weeks of referral followed by a transfer meeting<br>• During the transfer any crisis was managed by CAMHS<br>• GP and CMHT received a detailed discharge letter in majority of cases.<br>• Only half of the cases had a planning meeting, and attendance at meeting was incomplete. | DF reviewed from conference presentation - searches conducted for further details for follow-up – none available |
| Heflinger and Hoffman (2008)<br>USA | Young people with Serious | The study examines publicly funded transition age youth | Secondary analysis of the TennCare data for 2003 on | • The SED group was the largest high risk group for publicly funded youth. | Focus on medicare not |

| Author (year) Country | Population | Focus of Research | Design Sample size | Findings | Included in review & quality assessment score |
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| | Emotional Disturbances | in Tennessee to describe the numbers and type of youth in need of care planning | publicly funded youth aged 14-17 N=134,569) Youth with SED (n=24,454) | • 79% were high risk with all criteria for SED<br>• Slightly more than a quarter (28%) of SED group were also in the behaviour disorder category (e.g. ADD, CD, ODD) | relevant to UK setting |
| Islam et al (2015) Track study | Young people from Track study (see below) who did not transfer to AMHS | To investigate healthcare provision for young people with ongoing mental health needs | Secondary analysis of the TRACK study data (n = 64) of young people in Track study who were not transferred from CAMHS to AMHS. | • The most common outcomes were discharge to a general practitioner (GP; n = 29)<br>• Ongoing care with CAMHS (n = 13), with little indication of use of third-sector organisations. Most of these young people had emotional/neurotic disorders (n = 31, 48.4%) and neurodevelopmental disorders (n = 15, 23.4%).<br>The study demonstrated that GPs and CAMHS have been left with the responsibility for the continuing care of young people for whom no AMHS could be identified. This decreases the capacity of CAMHS to respond to new referrals and may leave some young people with only minimal support on leaving CAMHS. | |
| Manteuffel, Stephens, Sondheimer, and Fisher (2008) USA | Transition age young people, aged 14–15, 16–17 and 18+ years old in 45 different federal care systems in 36 US states. | To examine characteristics, service use, clinical and functional outcomes of TAY enrolled in systems of care and receiving services for SED and SMI, using data from a national evaluation of the Children's Mental Health Initiative | Quantitative cohort study.<br><br>Cross sectional descriptive study and longitudinal outcome study (between 1997 and 2006.) n = 8484 in the descriptive study and n= 3613 in the outcome study | Found that more transitional services were needed – less than 10% of 16-17 year olds received transitional support.<br><br>Families of older adolescents (i.e., 16–17 year-olds) were less likely to receive respite services than families of younger (i.e., 14–15 year-old) adolescents in the first 6 months of receipt of services<br><br>Differences in the severity and types of problems experienced by transition-age youths and changes in the use of services indicate the need for youth- and family-centred approaches | Included in Reale and Bonati Quality score 8 |
| Memarzia et al (2015)<br><br>UK | Young people preparing to leave CAMHS | The aim of this study was to determine predictors of mental health and<br><br>social adjustment in adolescents leaving | A cohort (n = 53) of 17 year olds were interviewed and assessed when preparing to leave adolescent services and again | At discharge 34 (64%) met DSM IV criteria for a current psychiatric diagnosis and only 3 (6%) participants met operational criteria for successful outcomes at follow-up. Impairments in mental health, lack of employment, education or training and low preparedness were associated with poor outcomes. | |

| Author (year) Country | Population | Focus of Research | Design Sample size | Findings | Included in review & quality assessment score |
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| | | mental health or social care services | 12 months later. Their mental health and psychosocial characteristics were compared to a same-age community sample group (n = 1074). | The findings suggest the current organisation of mental health and care services may not be fit for purpose and even unwittingly contribute to persistent mental illness and poor psychosocial outcomes. A redesign of services should consider a model where the timing of transition does not fall at the most hazardous time for young people, but is sufficiently flexible to allow young people to move on when they are personally, socially and psychologically most able to succeed. Assessment of a young person's readiness to transition might also be useful.<br>A youth focused service across the adolescent and early adult years may be better placed to avoid young people falling through the service gap created by poor transitional management. | |
| Singh et al. (2010)<br>Paul et al (2013)<br>England<br>UK<br>Track | Young people in English trusts that transitioned from CAMHS to AMHS in a calendar year, service users, parents, clinicians. | To evaluate the process, outcomes and user and carer experiences of transition from CAMHS to AMHS | Case note analysis of 154 young people transitioning to AMHS, including descriptive statistics<br><br>Young people (n=11) CAMHS service users, parents (n=6) CAMHS clinicians (n=6) and AMHS clinicians (n=3) | The transition process is poorly planned, and is a poor experience. The study findings highlighted the need for increased continuity of care and transition meetings.<br>42% of the 154 case note participants did not transition into AMHS - main reasons were:<br>• Found that transfer from CAMHS to AMHS was common but good transitional support was less common<br>• Only 4 young people received 'optimal transition'.<br>• 131 (85%) were thought to be suitable for transfer to AMHS<br>• 102 (66%) were referred<br>• 90 (58%) were accepted by AMHS<br>• 76 (49%) at least one appointment was attended (referral accepted)<br>• 12 (9%) referral refused by YP/carer<br>• 12 (9%) of CAMHS thought AMHS would not accept referral<br>• 7 (5%) refused by AMHS | Paul et al (2014) Score 28/36<br>Reale and Bonati (2015) Quality score 12 |

| Author (year) Country | Population | Focus of Research | Design Sample size | Findings | Included in review & quality assessment score |
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| | | | | ○ Reasons included: Did not meet criteria, no suitable service available, alternative suitable service<br><br>• Transfer does not guarantee successful transition. Optimal transition was described as:<br><br>1. Continuity of care (engaged with AMHS 3 months after transfer)<br><br>2. A period of parallel care & joint working between CAMHS and AMHS<br>3. Meeting (involving YP and AMH provider) prior to transfer<br>4. Information exchange | |
| Learning disability, ADHD/ASD | | | | | |
| Hall et al. (2015) England<br><br>Part of TRAMS study | ADHD NHS Mental Health Trusts (MTHs) in England | To investigate the transition process and current services for adults with ADHD, to identify gaps in care and areas for service improvement. | Survey sent to all 53 MTHs in England, with responses from 37 trusts (70% response rate). Completed by 36 psychiatrists and 1 psychologist. | • Over half (22/37 59%) did not know how many adults with ADHD were currently in care of their trusts.<br><br>• Over half (20/37) did not know how many YP with ADHD transitioned into adult services<br><br>• 54% had a written transition from CAMHS to AMHS but only 22% (8) had a transition for Paediatrics to AMHS<br><br>• A third (35%) had shared care protocol (SCP) for ADHD medication in adults<br><br>• 89% reported not having a dedicated support role to support the transition<br><br>Study concludes:<br>• ADHD transitions need to be underpinned by clear, structured guidelines and protocols, with routine data collection, information sharing across CAMHS to AMHS | DF quality assessment score:<br><br>29/36<br><br>Included in Reale and Bonati (2015) Quality score 9 |

| Author (year) Country | Population | Focus of Research | Design Sample size | Findings | Included in review & quality assessment score |
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| | | | | • An increase in the commissioning of specialist ADHD clinics is needed to ensure ADHD adults / emerging adults have access to appropriate care and support. | |
| Ogundelle (2013) Liverpool | YP with ADHD in Liverpool | To review current practice<br>To design a transitional care pathway | Case note review of all young people on specialist ADHD database who reached 16 over a 2 year period N=104 eligible young people | • 19 (18%) were referred to CAMHS<br>• 68 (65%) were discharged after voluntary discontinuation of medication and non attendance at clinic<br>• 16 (15%) were successfully transferred to CAMHS (3 had been discharged)<br>• Low rate of successful transitions to AMHS<br>• Care pathway designed<br>o More flexible referral pathway<br>o Multidisciplinary<br>o Transition to commence at age 13<br>o Transition co-ordinator<br>o Review team | DF reviewed (26/36)<br><br>Emailed for evaluation of pathway |
| McCarthy et al (2009) UK | YP with ADHD prescribed pharmaco-therapy | To the determine the prevalence of methylphenidate, dexamfetamine and atomoxetine discontinuation in young adults | Secondary analysis of General Practice Research Database (GPRD) (3 million active patients across UK) – data from Jan 1999 to Dec 2006. Analysis of data from young people aged 15-21 years with a least one prescription of one | There was an overall significant increase in prescribing of drugs for treatment of ADHD over the 8 year period,<br>• In 1999 the prevalence for drug prescribing for male patients aged 15-21 was .88 per 1000. In 2006 the prevalence per 1000 patients 5.06.<br>• In 1999 the prevalence for drug prescribing for female patients aged 15-21 was 0.06 per 1000. In 2006 the prevalence per 1000 patients 0.77.<br>There was an interaction with age, with a greater increase in prescribing in younger patients. | |

| Author (year) Country | Population | Focus of Research | Design Sample size | Findings | Included in review & quality assessment score |
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| | | | of the 3 drugs (N=1636). All patients aged 15 (with prescription) in 1999 were followed up until 2006. | Longitudinal cohort analysis found a discontinuation of prescribing in older adolescents and young adults, with no patient receiving treatment by age 21.<br>• Raises questions on the treatment of young adults with ADHD once they leave paediatric services / education<br>• May reflect the poorly developed services for young adults with ADHD in AMHS (lack of clinicians with expertise in ADHD) | |
| Taylor et al (2013) England Sheffield | Young people with ADHD | To identify the ongoing support needs of young people with ADHD attending a paediatric neuro disability clinic. | Case note review of all young people aged 14 or over on Sept 2007 seen in a paediatric neuro-disability clinic N=139 young people | • 102 (75%) were on medication<br>• 50% had well controlled ADHD (with no need of AMHS)<br>• 17% had offended<br>• 71% had at least one co-morbid condition<br>• 46 (34%) received intervention from CAMHS<br>• 37% were likely to need to transition to AMHS (depression, anxiety or ASD)<br>• 36% were likely to benefit support from CNS or GP or adult mental health specialist<br>• Study did not include YP referred directly to CAMHS in area (without attending the paeds clinic). These YP may have more severe symptoms and different needs on leaving CAMHS.<br>• YP with ADHD leaving paediatric services should have individual plans which encompass their psycho-social, educational/employment needs in addition to health care needs.<br>• A number of options should be available for follow-up. | Included in Paul et al SR<br><br>Score24/36<br><br>Also reviewed by DF<br>Score 28/36 |

| Author (year) Country | Population | Focus of Research | Design Sample size | Findings | Included in review & quality assessment score |
|---|---|---|---|---|---|
| Taylor, Fauset & Harpin (2010) UK | 14–16 year olds with ADHD attending a paediatric neurodisability clinic | To identify the service needs of young people with ADHD | Case note review and descriptive statistics.<br><br>n=139 participants | Identified gaps in transition services for young people with ADHD but also found that 50% of participants had 'well managed' ADHD and only 37% needed to transition to AMHS. | Paul et al (2014) Score 24/36 |

Table 5: Studies Exploring Systems or Approaches to Support Transitions

| Author (year) Country | Population | Focus of Research | Design Sample size | Findings | Included in and quality assessment |
|---|---|---|---|---|---|
| Mental Health | | | | | |
| Singh, Paul, Ford, Kramer, and Weaver (2008) UK | CAMHS in Greater London | To identify and analyse existing transition protocols in Greater London, and identify annual transition rates | Questionnaire survey of 65 teams. Content analysis of protocols.<br><br>42/65 CAMHS responded to survey. | 13 transition protocols were in operation (and 2 in draft format)<br>Not all protocols met requirements of NSF.<br>Transition policies and restrictions (such as education status and age range) varied amongst services.<br>Age ranged from 16-21 years for transition.<br>All 13 protocols reviewed considered enduring mental health problem or likelihood of enduring mental health problem as criteria for referral to AMHS (and services may have different concepts of enduring mental health problem).<br>All protocols identified the YP as central to the transition process, none identified how the YP was to be prepared for transition.<br>Three quarters had not provision for follow-through if patient was not admitted to AMHS. | Paul et al (2014)<br>Score 30/36 |
| Thomas, Pilgrim, Street, and Larsen (2012) UK | 122 specialist CAMHS and EIP (Early Prevention in Psychosis) /AMHS in England | To review progress towards creating a better youth mental health system and to make recommendations to improve the experiences of vulnerable young people in transition | Online surveys and case study analysis. Findings were thematically categorised in descriptive statistics. | Found lack of services for transitioning for young people with psychosis. Problems included identifying young people with psychosis, limited outreach work, lack of funding, and reluctance to seek out services due to stigma. | Paul et al (2014)<br>Score 22/36 |

Table 6: What works? Studies describing findings from evaluations of interventions / approaches to improve transition

| Author (year) Country | Population | Intervention | Design Sample size | Outcomes & Findings | Included in and quality assessment |
|---|---|---|---|---|---|
| Mental Health | | | | | |
| Gilmer (2012) | Young people with mental health problems (aged 21) | **Intervention**: Outpatient programme for transitioning young people focus on independent living skills, education and vocational skills, socials skills **Comparison:** standard care for adults with mental health and substance abuse concerns | Quasi-experimental<br><br>Intervention n=931<br><br>Comparison n=1574 | Inpatient admissions and emergency service visits, outpatient visits<br><br>*NICE (2016) note that this study is primarily an advanced audit (no assessment of service need & so overall outcome of 'service use' is indicative rather than a direct outcome. It does not provide evidence on whether the change in service provision enhanced young people's transition.* | NICE guidelines (2016) +/+<br><br>Paul et al (2014) |
| Stryron et al (2006) USA | Young adults aged 18+ with psychiatric, neuro-developmental cognitive, social, emotional problems transitioning out of CAMHS<br><br>, | **YAS** – a service including clinical and residential case management, planned step up/step down care with more / less services. Aimed to help YP develop viable social support systems, achieve educational success and learn pro social adaptive behaviours and independent **living skills.** | n=60 high risk young people (structured interviews)<br><br>Face to face interviews with participants (n=12 qualitative interviews) Survey of clinicians<br><br>Case file review<br><br>Standardised measures of: mental health symptoms and functioning; quality of life measures. | Strengths-focused treatment planning (SFTP) and community-focused treatment planning (CFTP) lead to fewer symptoms, less loneliness, fewer mental health problems, higher functioning and greater satisfaction with services. SFTP contributed significantly to greater quality of life and CFTP to fewer arrests. Clients using YAS were more likely to use both SFTP and CFTP. Youth in a youth to adult service were more likely to report an overall healthier and more satisfying lifestyle and fewer health/mental related problems | Paul et al (2014) 27/36<br><br>Embrett et al (2016)<br><br>DiRezze et al (2015) |
| Dresser et al (2015) USA | Young people with SMC attending a new TIP site in Muskegon County | **TIP** | 2 studies Study 1 focused on implementation of model Study 2 focused on outcomes of participants<br><br>n=29 participants (59% female and 41% male) Average age 17.7 Mixed ethnicity | Process indicators included: (a) community life and living situation (i.e., living in community settings versus treatment or restrictive setting; family or independent living setting; living with friends or "couch surfing;" detention, jail, residential treatment, or AWOL; not on probation) and (b) education and employment progress indicators (i.e., employed and/or attending school; attending school or GED program; employed; graduated high school or completed | |

| Author (year) Country | Population | Intervention | Design Sample size | Outcomes & Findings | Included in and quality assessment |
|---|---|---|---|---|---|
| | | | Follow-up study<br>No control group | GED during this evaluation period; attending college).<br>At follow-up | |
| Haber et al (2012)<br>USA | Families of children experiencing Wraparound services<br><br>Young people<br><br>Service providers | To examine possible challenges that could interfere with use of wraparound transitioning youth with mental health conditions | Two sources of data used. Archival data from 2 evaluations.<br>1. Longitudinal outcome study of caregivers (n=218)<br>2. Evaluation of wraparound service involving YP, caregivers (n=80), and service providers<br>Self completion tools including Caregiver Strain questionnaire, Family Life questionnaire, Participant rating form.<br>(n=218 families)<br><br>No comparison group | These services were designed to offer transition support for youth with severe mental illness. It found that mental health symptoms did change positively following the intervention.<br><br>Study 1 found:<br>Older age was associated with higher levels of caregiver strain. High levels of family needs that could be targeted by community based organisations, and<br><br>The findings underscore the importance of helping to link caregivers with potential sources of support and connectedness<br><br>Study 2 found:<br>Older young people (aged 16-17) perceived teams as less cohesive than younger participants.<br><br>A systems need, including the views of parents but place increasing weight on views of youth, tipping the balance towards greater youth voice. | |
| Haber et al (2008) | 14 –21 years<br>Transition aged youth and young adults with serious mental health conditions (TAY w/SMC) | **Partnership for Youth Transition (PYT)**: A 4-year, multisite demonstration to support five comprehensive, community-based transition support programs for TAY w/SMC in locations across the country<br><br>Four of the sites used **TIP** (see Clark et al, Dresser et at ), and one used Assertive Community Team (ACT) | n=193<br>Longitudinal study<br>Baseline: Demographic and historical assessment designed to gather information on TAYw/SMC's prior to entry into programme;<br>Follow-up: quarterly assessments on indicators of transition-related progress | Young people with SMC showed transition progress on all or most of the domains examined<br>Most consistent improvements were on indicators of educational advancement and employment progress and the composite of these variables, the productivity indicator<br><br>No detail on mental health outcomes or attendance at mental health services | DiRezze et al (2015)<br><br>0.82 |

| Author (year) Country | Population | Intervention | Design Sample size | Outcomes & Findings | Included in and quality assessment |
|---|---|---|---|---|---|
| | | | and challenges (e.g. criminal justice involvement, interference with daily activities) | | |
| Cappelli et al (2014) Evaluation<br><br>Cappelli et al (2015) (Logic model) Canada | Young people with mental health illness | **Youth Transition Programme (YTP)**<br>*Shared care management model*: Transition team (CAMHS community AMHS, addiction services), staff trained in adolescent transition, and a co-ordinator. A clinical review committee to review complex cases. Social work input, counselling, and family engagement.<br>*Process* involved assessment of YP's needs; referral to appropriate service; counselling and monitoring of the YP by social worker and co-ordinator. Interviews with YP with families with child and then alone. | Evaluation (Cappelli et al 2014) involved follow-up study of young people (n=215) | Anticipated outcomes (described in logic model): no findings presented.<br>Overall aim:<br><br>Short term: (3-6 months)<br>increased engagement with YP with mental illness and their family;<br>increased appropriate referrals;<br>increased awareness among key stakeholders on the transition issues.<br>Intermediate: (6 to 2 years)<br>Decrease in crisis driven reconnection<br>Decrease in drop-out<br>Decrease in wait time<br>Long term: 2 years +<br>Increase of implementation of policy e.g. transition protocols; formal systems of referrals<br>Increase in development of similar and related community services. (e.g. scalability)<br>Increase in number of successful transitions<br>Increase in self advocacy skills among yp | Follow-up searches of key papers |