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

Executive Summary



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Why did we start

Evidence from the rest of the UK and elsewhere, suggest that many young service users and their families, find the transition from Child and Adolescent Mental Health Services (CAMHS) to Adult Mental Health Services (AMHS) challenging. The organisation and culture within these services are somewhat different and many young people ‘fall through the net’ with the likelihood of poor outcomes. When we started our study, very little was known about service pathways and outcomes related to the transition. We were funded by the HSC Research & Development Division of the Public Health Agency Northern Ireland to examine the transition pathways and experiences of young people with mental health problems as they moved from Child & Adolescent Mental Health Services to Adult Mental Health Services. 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?

What did we do?

We undertook:

- (a) A comprehensive mapping exercise in which we examined policy and practice related to the transition process in each of the Health and Social Care Trusts.
- (b) A case-note review of all 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.
- (c) Focus group and in-depth interviews with CAMHS and AMHS multi-disciplinary teams, managers and commissioners in each Trust.
- (d) In-depth interviews with service Users (SUs), their parents/carers and professionals to explore their experiences during the transition from CAMHS.
- (e) An interactive workshop with service users, clinicians and other stakeholders to synthesise findings and recommendations for service improvement.
- (f) A rapid review of the international evidence on the transition from CAMHS to AMHS.

What answers did we get?

We found considerable differences between the Health & Social Care Trusts in the level and type of mental health services available for young people and between their processes and policies for transition. We found widespread anxiety and concerns about the transition to AMHS, much of which appears fuelled by poor communication and misinformation. Staff in CAMHS and AMHS, respectively, knew little about each other's practice and policies. We noted particular difficulties for young people with a diagnosis of autism and ADHD. We found that 375 people were eligible for transition between January 2010 and December 2014. The median age for referral to CAMHS was 14 years and males were more likely than females to be referred at a younger age. From the 252 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 referring clinician before acceptance. Five percent (n=13) were rejected on referral. None of the case notes showed evidence that all the elements for an optimal transition had been met.

What should be done now?

There is an urgent need for the development of information materials and educational tools about the transition process and for mental health services, generally. We would like to see such tools developed with a range of young service users, possibly diagnosis specific. 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. 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. Some 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. Such a service could be piloted in Northern Ireland.

Background

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. 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. Adolescence 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.

Young people and mental health

The rates of mental health problems increase during adolescence. Recent epidemiological studies [1] 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 [2, 3]. 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 [4-6]. Late adolescence and early adulthood is recognised as a time of increased risk for developing mental health problems such as depression with evidence that approximately half of all mental disorders begin in middle teenage years and three quarters by the mid-twenties and some more serious disorders, such as psychosis, emerge during this period [7]. 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[8].

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[9]. 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. 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 [10] 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 youth to adult oriented services can be associated with increased risk of non-adherence to treatment, loss to follow-up, and poorer health outcomes [11]. Between 30-60% of young people drop out of treatment with young socially isolated males most likely to disengage[11]. 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 [12].

The IMPACT study

The Bamford Review [13] set out a strategic vision for the development of a service for children and young people with mental health problems. 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, there has been a notable failure to engage with the education and voluntary sectors. 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[10]. 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. There are concerns 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 this, there is scant evidence on the extent of the problem. Also lacking is a comprehensive multi-perspective understanding of how the various structural and cultural challenges to good transitional pathways may be addressed. 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.

Study aim and research questions

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?
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The research was conducted over a 3-year period and involved four stages (Table 1): a mapping study; case note reviews; in-depth interviews with service users, parents/carers and mental health professionals; and an evidence review. 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 were sequentially tested and refined our theoretical assumptions about the transition pathway and the constituent factors underlying barriers and facilitators to good care.

Ethical approval and research governance

An application for ethical approval was submitted to the Office for Research Ethics Committees (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 met bi-monthly throughout the project, and informed all aspects of the project

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.

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 to 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.

Results

Mapping of Services

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. 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. One fifth of the total population are aged 15 years and under; 25% are aged between 16 and 34 years (NISRA¹).

¹ <http://www.nisra.gov.uk/index.html>

Table 1: Summary of study stages

Stage	Approach	Number of participants
Stage 1	<p>Mapping of services and interviews with service providers</p> <p>Feedback workshop with service providers and service users</p>	<p>Service Mapping: All five Trusts in Northern Ireland</p> <p>13 mapping tools completed</p> <p>Belfast HSCT 6, South Eastern HSCT 2, Southern HSCT 3, Northern HSCT1 (representing 3 teams), Western HSCT1 (representing 2 teams)</p> <p>Interviews and focus groups N=149</p> <p>Individual interviews</p> <p>Statutory Services (n=8)</p> <p>Community Voluntary Sector (n=14)</p> <p>Focus groups & meetings N=159</p> <p>2 transition panel meetings (n=21)</p> <p>4 academic meetings (n=80)</p> <p>3 staff team meetings (1 AMHS CMHT, 2 CAMHS) (n=26)</p> <p>4 focus groups (n=32)</p> <p>Interactive Workshop N=41 attended</p>
Stage 2	Case note review	N=373 cases
Stage 3	<p>Interviews with current and past service users</p> <p>Interviews with parents/carers</p> <p>Interviews with clinical service providers</p>	<p>Young people N=25</p> <p>Current service users n=18 (Core group) **</p> <p>(**Follow-up interviews n=10)</p> <p>Service users with transition experience (supplementary sample) n=7</p> <p>Individual interview with parents/carers N=12</p> <p>Includes interviews with parents of core group n=7</p> <p>Individual interviews with parents/carers of children who had recently made the transition (but were not part of the core group) n=5</p> <p>Plus 1 focus group interview with parents/carers n=5</p> <p>Mental Health Professionals N=26</p> <p>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</p>
Stage 4	Rapid evidence review	Not relevant

Table 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 NISRA²

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 CAMH team in the remaining Trusts). All five Trusts returned their most recent transition protocol.

Summary of Mapping of Services

- 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; the Eating Disorder Service and the Forensic Child and Adolescent Mental Health Service.
- Sixteen core teams deliver the CAMH services at a local level across the five HSC Trust areas.
- Overall, from the 2014/2015 data 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 years in all 5 Trusts but referral to adult services can occur 6 months before the transfer date. 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.
- Accurate data on the numbers of potential and accepted referrals were not available from the returns from all Trusts.

²<http://www.nisra.gov.uk/demography/default.asp136.htm> accessed Oct 2016

Retrospective Case review

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 AMHS because of a lack of an appropriate service; client refusal; 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.

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. We also sought the assistance of service managers who were able to identify additional missing cases. 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).

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.

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.

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%).

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. 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.

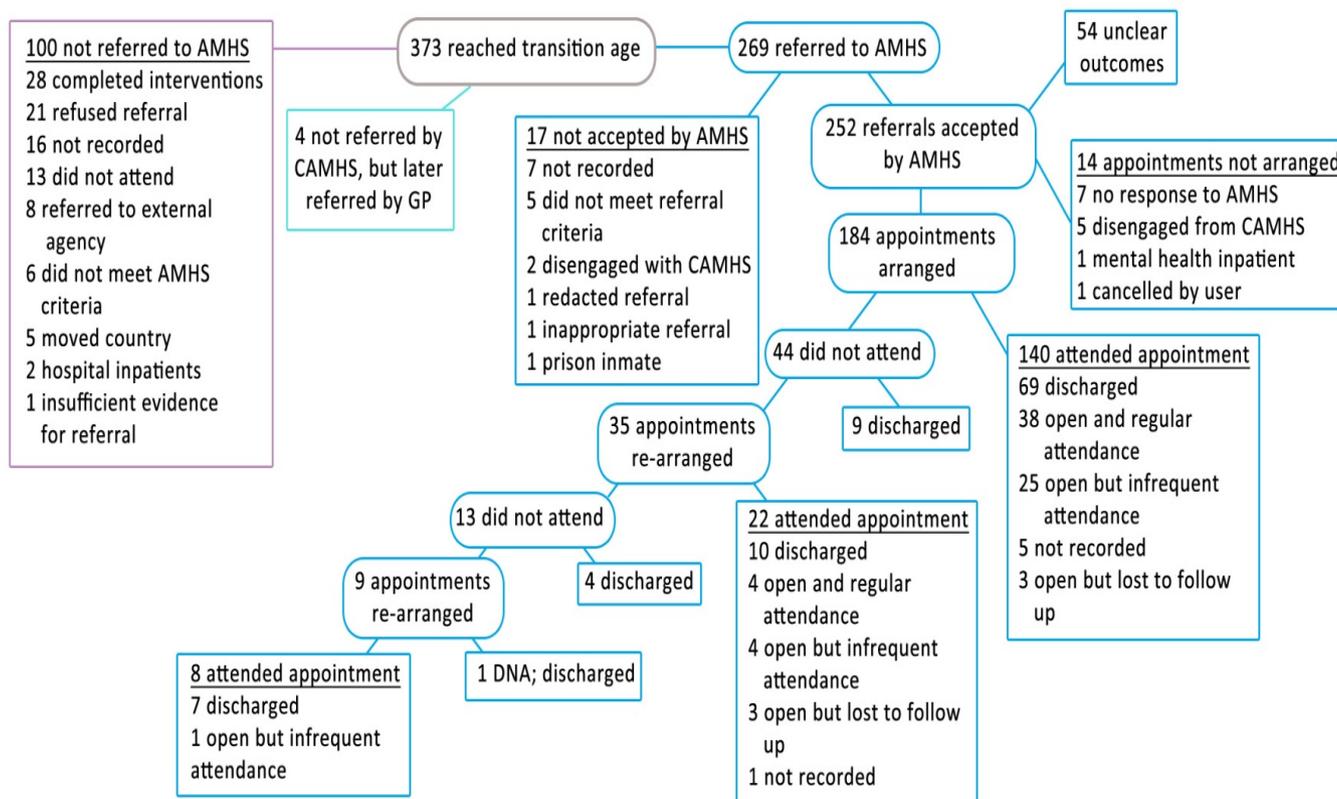
Two hundred and forty-four service users (67%) were recorded as having a family history of mental illness, predominantly a mother (n=158). In 183 cases both parents were recorded as having a mental illness. Sibling mental illness was recorded for 62 (26%) people. The median age for referral to CAMHS was 14 years (Mean=14.2, SD=3.2). Males were 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.

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 rejection by AMHS are given in Figure 4.0. However, those rejected by AMHS were rejected before anything like a transition meeting took place. This means that they could not have experienced continuity of care, a transition planning meeting or a period of parallel care. Thus, 252 people (67%) crossed the transition boundary. (Figure 1).

Figure 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. 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. 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%). Where such a discussion was recorded in CAMHS notes, we examined the content 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 criterion, 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 96 cases (38%) and in 73 cases (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 at 11 (11%) of these meetings.

Transfer of Care

Transfer of care between CAMHS and AMHS was managed in two ways. Firstly, a joint appointment could take place between CAMHS, AMHS and the young person; this appointment would discuss the end of CAMHS care and transfer care to AMHS. Secondly, the young person would be formally discharged from CAMHS during an appointment, and would then receive 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 prevalent (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 cases not referred by CAMHS were later referred by their GPs and accepted by AMHS.

Meeting Optimal TRACK Criteria for Transition

In the TRACK study[14], 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, in this study, 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 3 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%)

Of the 252 people transferred to AMHS, 100 (40%) were later discharged by AMHS while a 72 (28%) remained in attendance. Fourteen people had yet to receive an initial assessment and 6 cases were open but lost to follow up. Information for another 6 people was not available. Years of contact with CAMHS and H&SC Trust were significantly associated with transition. A prescription for anti-psychotic medication was the strongest predictor of transition while neighbourhood deprivation (NI-MDM) appears to have no significant effect on transition.

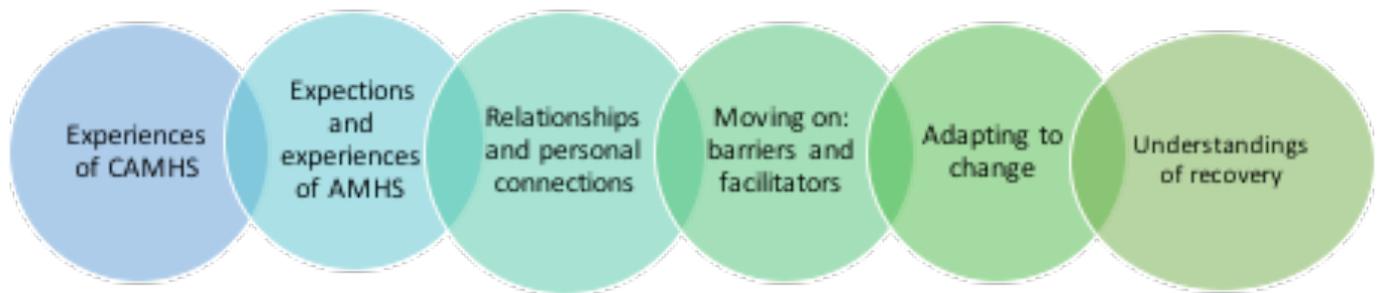
Consultation with young people, carers and service providers

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.

The experience of transition

Our analysis of the young service user interviews has 6 sub-themes (see Figure 2) 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 2: Part 1 analysis: The experience of transition



Key Findings

- The aspects of CAMHS care that young people and parents valued are summarised within four sub-themes: (1) ethos and culture of care; (2) accessibility and support; (3) relationships; and (4) authenticity of caring.
- 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.
- CAMHS staff were described as ‘extremely helpful,’ in providing care and this was not only important for service users but also for parents who felt included within the care plan for their child.
- 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.
- The perceptions and expectations of adult services ranged from the very positive to the highly negative, and everything in between. 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.
- There was scant evidence that such perceptions 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.
- Adult services appear to be much more stigmatised and therefore, stigmatising than CAMHS and this deterred a full engagement with services.
- CAMHS staff, service users and family caregivers lack good knowledge about systems and approaches within adult services.
- Commonly parents/carers were concerned about being excluded in the decision-making process about care and/or being left uninformed.
- It was believed that family therapy was no longer available after the transition to Adult Services and this added to the parental anxiety.

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- Service users commonly described feeling a sense of rejection by CAMHS, feeling that they were no longer wanted by CAMHS or their CAMHS keyworkers.
 - The gap between successive appointments with CAMHS and Adult Services was reported as one of the worst aspects of the transition process.
 - While the provision of parallel or overlapping care, during which, the young person is seen by both CAMHS and AMHS, is considered as well-integrated, few people had experienced this.
 - Gaps and potential risk areas included the lack of psychotherapists, clinical psychologists and the crisis assessment procedure at hospital Emergency Departments.
 - 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.
 - There is a suspicion among community organisations holding formal Health Trust contracts that they are 'being used' in order to address breaches in the waiting lists within CAMHS.

Rapid Review Findings

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

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- positive relationships between young person and service provider.
 - continuity of care (therapeutic care).
 - young people friendly services e.g. settings and information.
 - 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 and finance.

Conclusions

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. The proportion of people who succeeded in making the transition to adult services is greater than that estimated by the clinicians and managers during the mapping phase of the study.

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 [14-18] and services have continued to respond to these findings and to other pressures.

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 HSC 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 are 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 North Down and Ards 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 HSC Trusts have much better access to a range of well-established voluntary sector organisations compared to areas of 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 persons' 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 may 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.

There is no singular or 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 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 organisational 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.

Recommendations

Standardised care

The differences between Health & Social Care Trusts highlighted in this report are only partly explained by geography and resources. The optimal level and type of service provision to young people, regardless of area, should be considered at government level and a higher level of standardisation sought across Trusts and services. The issue of differential service provision for young people with autism or ADHD is particularly concerning and requires urgent attention at policy level.

The guidelines (NICE, 2016) for good practice for young people making the transition to adult services which were published towards the end of our study, should be made widely available to clinicians, service users and families. They also require monitoring to ensure adherence.

Young people with ADHD, ASD, eating disorders, and young people leaving care were identified as 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. Leadership is required from both commissioners and senior management to support collaborative and effective partnerships between CAMHS, AMHS and the community and voluntary sectors.

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.

Communication between services

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.

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.

Parents' support: 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. Agreement about continuity of care and continued parental involvement is possible and we recommend a flexible, individualised approach to this that takes into account the developmental and personal needs of the young person. 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.

Separate services for 16-25 year olds

There was considerable interest, 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. While there are apparent advantages to an extended or transitional youth service, we currently lack robust evidence on their effectiveness.

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