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Knowledge Exchange Seminar Series (KESS)

IMPACT: Improving mental health pathways and care for adolescents in transition to adult services in Northern Ireland.

Funded by Public Health Agency, R&D

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Introduction and background to the study

Young people face many significant and challenging transitions in their adolescent and teenage years, at a social, biological and psychological level. 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. 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. 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). It 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).

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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 and Lowen, 2010, Brindis C et al., 2002, Brindis et al., 2007) and a recent study in Northern Ireland (O'Connor et al., 2010) indicated that 10% of young people aged 15 and 16 years have self-harmed. A survey of mental health disorders in 2004 across England, Scotland and Wales found that one in ten children and young people aged 5-16 years suffer from a diagnosable mental health disorder, and that nearly 80,000 children and young people suffer from severe depression (Green et al., 2005). As with physical ill health, increased risk of mental illness is associated with social disadvantage and relative poverty. Children from poorer backgrounds, children in care, asylum seekers and children who witnessed domestic violence were all at higher risk of developing mental health problems, as are children and young people in contact with the criminal justice system (BMA, 2006; Murphy & Fonagy, 2012). Similarly the 2004 B-CAMHS survey found the prevalence of mental health disorder was greater in children and young people living in a lone parent family (16%) compared to those in a two parent family (8%); in families with neither parent working (20%) compared to a household with both parents working (8%) and in families where the weekly household income was less than £100 a week (16%) compared to households with an income of £600 or more (5%) (Green et al, 2004).

Child and Adolescent Mental Health in Northern Ireland

While little epidemiological data exists 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. Young people with caring responsibilities or with a longstanding illness or disability were also more likely to report such emotional and mental health problems (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) with the number of males taking their own life approximately five times higher than females (Samaritans, 2013). Not meeting the mental health needs of young people has significant long term financial costs. The human cost is immeasurable.

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Extrapolating figures from British and international studies it is estimated that (at least) 10% of approximately 45,000 children and young people aged 5-15 in Northern Ireland will have a moderate to severe mental health disorder requiring intervention from specialist CAMH services (Meltzer et al, 2003). Many young people who receive such an intervention will require mental health care beyond the CAMHS transition boundary. This transition from CAMHS to AMHS has been long identified as a policy concern, affecting service users, carers, families and practitioners (DCSF, 2008, DH/DCSF, 2010). There is evidence that some young people are lost to services at this crucial time, that many struggle to move between services, and others, particularly those with learning disabilities, and neurodevelopmental disorders (ASD, ADHD) find that their needs are not catered for within adult mental health (Pugh & Meier, 2006; Marcer, Finlay & Baverstock, 2008). Evidence 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 and Appelqvist-Schmidlechner, 2010, Suhrcke et al., 2007). For the year 2008/09 the cost of mental illness to the Northern Ireland economy was estimated at £3.5 billion (DHSSPS, 2010). Despite these consequences, “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).

Making the transition from CAMHS to AMHS

While guidance for transition is outlined in the DHSSPS Service Framework for Mental Health and Wellbeing (2010) there is currently no regional framework or policy governing the transition from CAMHS to AMHS in Northern Ireland. The structure of services, and procedures and protocols for transition between services differs across each of the Trusts. The Bamford Review of Mental Health and Learning Disability (Bamford, 2006) made a number of recommendations for CAMH service development, including greater interagency working and arrangements. The Review questioned the strength of effective liaison and collaboration between services such as AMHS, education, social services, criminal justice and primary care and noted the failure within Tiers 1 & 2 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”. The

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review found that CAMH services in NI may be under resourced, patchy and inconsistent in their approach to adolescent care and service transition.

The RQIA review of Child and Adolescent Mental Health Services in Northern Ireland (RQIA, 2011) found that progress has been made in relation to some of the Bamford recommendations. The development of a purpose-built child and adolescent inpatient service (Beechcroft) has improved capacity and service. The review also welcomed the development of crisis intervention and eating disorder services as an alternative to hospital admission, although noted that these services were not equally distributed across Northern Ireland. Consultation with service users and carers on their CAMHS experience was generally positive, and for those who had experience of making the transition from CAMHS to AMHS most reported a positive experience. Not all service users had contact with staff from the Adult Services, however, before their transition took place. The RQIA states that ‘the interface between CAMHS and adult mental health must be addressed’ and that ‘more effective collaboration arrangements [be] established to ensure that the suffering in a child or parent does not go undetected or untreated’ (pg 199).

The Bamford Review also recommended flexibility in terms of the age at which a young person is transferred from child and adolescent services to adult services, stating that this should be in the best interest of the child. It is 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 IMPACT study

The IMPACT study is funded by the R&D division of the Public Health Agency. It is a collaborative project with key partners from the statutory and community and voluntary sector. The research team includes experienced health service researchers, including academic psychiatrists from the UK, Northern Ireland and the Republic of Ireland who have expertise in CAMHS and early intervention services. The project is supported by the five Health and Social Care Trusts. It has the backing of the Bamford CAMHS Implementation Group and the study will be incorporated within and supported by the newly established Northern Ireland Clinical Research Network for Mental Health. It is funded for 36 months, from April 2013 to end March 2016.

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Methodology

The IMPACT study models and extends the methodology used in the TRACK study in England as developed by Prof Swaran Singh and colleagues (Singh et al, 2010). They used a four stage approach to: (i) map CAMHS services and audit transition policies in six UK trusts; (ii) track the pathways and outcomes of all users who crossed transition boundary in a given year; (iii) conduct a diagnostic analysis across health services and voluntary sector and (iv) conduct qualitative interviews with service users, carers and care co-ordinators. A summary of their findings indicate that on the whole transition from CAMHS to AMHS is 'poorly executed and poorly experienced' and that even where protocols exist 'there is a policy-practice gap,' and many young people, especially those with neurodevelopmental, emotional or personality disorders fall through the gap between CAMHS and AMHS (Singh et al, 2010). In the Republic of Ireland, Professor Fiona McNicholas and colleagues also used the TRACK methodology to look at the CAMHS/AMHS transition process in Ireland. Findings from the first stage of their study indicate that this process is underdeveloped in Ireland, and that variation exists in the level of contact and quality of relationship between child and adolescent mental health services and adult services. Much of this variation they found to be underpinned by different service cultures and limited resources (McNamara, 2012).

Research Questions

The IMPACT study will provide data in a similar format to that gathered by the TRACK and ITRACK studies and create a potentially rich opportunity for cross comparison and analysis. It will address a number of questions, the key one being: What is the best way to organise mental health services for young people in Northern Ireland as they make the transition from CAMHS to adult mental health care?

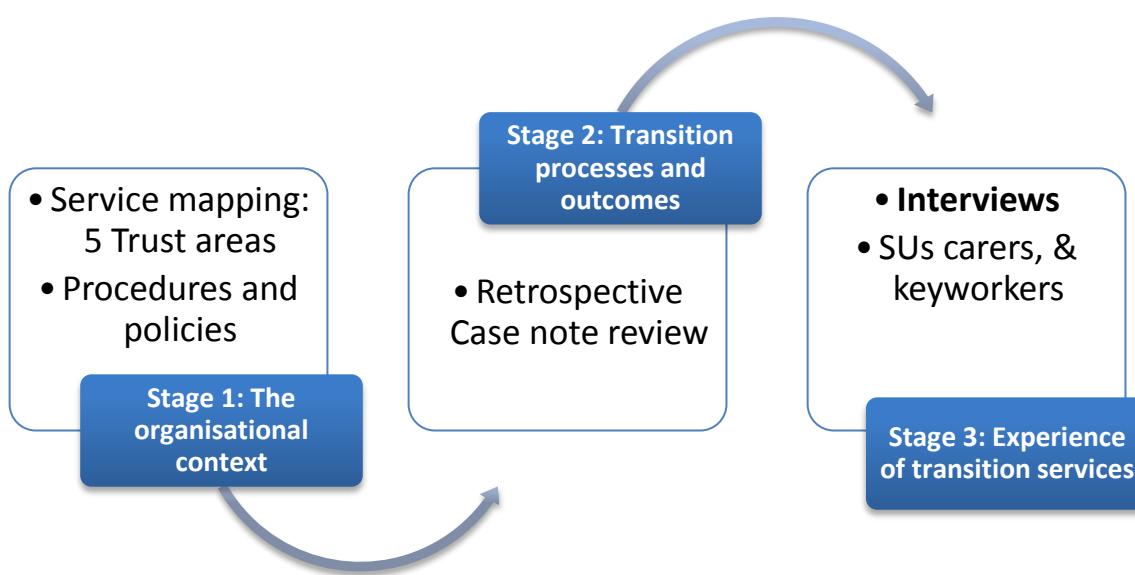
The dominant subsidiary questions relate to the following:

- How do mental health services in the Health and Social Care Trusts NI differ in their policies and provision of care for young people in the transition to adult services?
- How does social disadvantage influence health pathways and outcomes among young people?
- Which factors influence adolescents' engagement with services and continuity of care?
- What are the barriers and facilitators to CAMHS collaboration with adult mental health service, primary care and relevant community based agencies?

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The study is designed in three stages, and evidence generated from each stage will address the research questions from multiple perspectives and detail the transition pathways and experiences using qualitative and quantitative approaches.

Plan of investigation:



Improving our understanding of health inequalities related to disadvantaged communities, their engagement with services and related health and social outcomes are of particular interest to the IMPACT study. We need to ascertain if the needs of young people from different backgrounds may be accommodated more efficiently through an enhanced involvement with voluntary and community based organisations and improved liaison with general practice (Department for Children Schools and Families and Department of Health, 2008). Additionally, we consider this to be an ideal opportunity to explore 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).

In the qualitative interviews with the service users we will record their experiences of CAMHS, what they find helpful and challenging; how they get on with staff, the level of support they feel they have, and their expectations and concerns about leaving CAMHS. We hope to interview each young person (n=15) three times over the transitional period.

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The data produced from all parts of this study will combine to give a greater insight into experience of young people with mental health problems (who are known to services); the challenges they face in accessing and staying in contact with services; and what is the experience of those who are in need of care beyond CAMHS.

Where we are now

We have engaged with key personnel in mental health in each of the five Health and Social Care Trusts, who have welcomed this study as necessary and timely. The collaboration of senior NHS managers and mental health clinicians is central to the success of this project, both in terms of facilitating the project across the Trusts and providing expert guidance.

We are currently working within Stage 1 and Stage 2 of the project. A Critical Interpretative Synthesis of the literature has been carried out to locate the study within current research and practice. The mapping of CAMHS services is underway and will be complete when interviews with key stakeholders are completed. The Case Note Review is due to start shortly in the Belfast Trust. This part of the project will chart service user pathways through transition boundaries and examine their outcomes in terms of referral process and level of engagement with services. It will review the care pathways, and referral outcomes, of young people who reach the transition boundary. Audit staff, trainee psychiatrists and a Clinical Studies Officer will be involved in the Case Note Review.

Plan for knowledge transfer of findings benefit health or social care.

The transfer of knowledge gained from the study for the benefit of health and social care is an explicit objective of the applicants and collaborators. The ultimate goal of the study is to address many of the deficiencies of transitional care, bringing a greater degree of consistency and coherence across the NI Trusts. This study is well supported by the stakeholders and committee members who will also be instrumental in fulfilling the recommendations arising from the study. Thus, the findings will be presented to health and social care staff at key gatherings and workshops. It will have considerable value to practitioners and commissioners.

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