

Young People's Experiences of Transition in Mental Health Services - A Key Perspective to Consider

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Introduction

Transition is the term used to describe the process of moving someone from one health service to another; it refers to the co-ordination, planning and preparation for supporting a person to leave one service and begin attendance at another. With regard to child and adolescent mental health services (CAMHS), transition to adult services, including adult mental health services (AMHS) typically happens at the age of eighteen - although this age boundary can vary, this in itself a cause for confusion and discontinuities in treatment.

Poor and disjointed care at point has been an area of high level concern in the UK and other European countries for at least the last decade. In the UK, the issue has been highlighted in a numerous government reviews, resulting in policies, guidance and initiatives to try and transform services and improve care across the child and adult service interface. For example, Future in Mind. Promoting, protecting and improving our children and young people's mental health and wellbeing [1] which sets out the national vision for children and young people's mental health, includes a section focused on transition and in 2017, NHS England introduced a new CQUIN - a Commissioning for Quality and Innovation contractual lever for CAMHS to incentivise services to improve their practice in supporting young people who need to transition to AMHS [2].

Why good care at the point of transition is crucial

Older adolescence is a high risk period for the onset of mental illness, with a variety of research studies highlighting that 75% of mental illness in adults has begun by the age of 24 [3] and that the age range of 16 - 18 is particularly critical [4]. The timing of the transition boundary between child and adult mental health services coincides therefore with the time when mental health problems are likely to emerge making early intervention and also continuity of care both especially important.

Alongside their mental health needs, many young people at the point of transition from CAMHS are facing other significant changes in their lives - for example leaving home for further education or to start work; this further emphasises that care and treatment, if young people need it, must be accessible and also a need for good information about where to go for help and about what is available. Discontinuity in care increases the risk of the mental illness becoming more severe, and young people accessing adult mental health care later, requiring longer and more complex treatments.

The poor care offered to young people at the point of making a transition from CAMHS to services for adults is marked by inadequate planning, little information, limited choices and problems with inconsistent referral thresholds. This includes being deemed ineligible for adult mental health services because their mental health needs are not severe enough. Research on this topic [5] has highlighted that young people with neurodevelopmental disorders such as Attention Deficit Hyperactivity Disorder (ADHD), emotional disorders, such as depression and anxiety, or emerging personality disorder are particularly affected.

The importance of young people's perspectives

Young people's views about health services are recognised in UK health policy as an important dimension in understanding whether services are working well or need adaptation. In the field of mental health especially, involving young people in the development, or review, of the services they use, has been a key part of government policy aimed at improving services - service user participation is, for example, a central plank of the NHS England Children and Young People's Improving Access to Psychological Therapies (CYP IAPT) programme.

Young people's experiences of transition not only shed light on the barriers they may encounter in trying to move to an adult service but also, highlight both some of the more subtle cultural differences between services that can impede transition - how there can often be a disconnect between policy recommendations and guidance and 'real life' practice. Young people's suggestions of what would make a difference also provide some valuable practical solutions to the barriers identified.

Their perspectives on transition highlight that the process is often poor because, at the most fundamental level, what planning there is, starts too late, with little preparation, inadequate information and then finally, a move that seems abrupt. Some young people have likened this to feeling like having to move from a "flooded house" - you have to move immediately to an unknown and un-chosen destination. Furthermore, young people frequently report feeling excluded from decisions about their care and that their wishes are disregarded, leaving them feeling disempowered, anxious and uncertain as to what will happen.

Other experiences relayed by young people reveal inadequate service co-ordination across different geographic areas. For example, young people describe problems resulting from their transition coinciding with them leaving home to go to university. Such moves, it seems, make it impossible for services to plan collaboratively. Alongside this, young people frequently describe situations of poor information transfer, leaving them having to re-tell their story or try and persuade adult services of their need for mental health care.

The confidence and expertise of staff to support those in transition to adult mental health services is another issue raised by many young people, with descriptions of different professionals holding different views about the same situation and a general failure of anyone taking charge of the transition planning, this often resulting in a failure to follow through on decisions agreed.

The 'markers' of good transitional care

In the TRACK research by Singh and colleagues [5], four optimal markers for transition were identified: good information transfer; a period of parallel care when both children's and adult mental health services would work together; joint planning and continuity of care. In many respects, these four markers match what young people say they need, namely: a plan that is built to match their individual needs, being involved in the process and to be offered some choices [6]. In addition, they identify that young people need information about adult services and what to expect and information about alternatives to NHS mental health services - for example, about counselling and other support provision that may be available in colleges and universities as well as those offered by the charity sector. And underpinning all of this, it is crucial that young people are given time to prepare for a move and that decisions should not be left until the last minute.

Conclusions

The perspectives and experiences of young people provide clear evidence that poor transitional care can have both immediate and long-term adverse consequences, with young people feeling disempowered, excluded from decision-making processes; in addition, the barriers they face can actually exacerbate some of the difficulties they experience as a result of their mental health difficulties.

Their perspectives for what is needed to improve transition in mental health services resonate with key studies such as TRACK [5], with NICE guidelines on this issue [7] and also the NHS England CQUIN.

The current high level of government interest in improving young people's mental health transitions is welcome, however, as this article highlights there are indications of an ongoing gap between policy and practice. Taking careful account of young people's perspectives and their suggestions for what would help them at this important service interface - truly involving them - would not only help to address some of the disempowering and damaging experiences many face, it might also help to address some of the cultural differences that beset mental health services for children and adolescents and those for adults. This in turn might foster greater shared 'ownership' by children's and adult mental health services of the problems of transition and provide impetus for the joined up approach to transition advocated by policy to become reality.

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