WHY STUDY TRANSITION IN YOUNG PEOPLE WITH ATTENTION DEFICIT HYPERACTIVITY DISORDER (ADHD)?

The core symptoms of ADHD are inattentiveness, impulsivity, and hyperactivity. People with ADHD are also more likely to develop other mental health problems and experience educational and social difficulties. Many young people continue to have symptoms of ADHD into their mid-twenties and sometimes beyond.

Transition is the process of moving from child to adult services, which usually happens at 16-18 years of age. For young people with ADHD, transition may be particularly challenging for a number of reasons:

- In some areas, there is no specialist service for adults with ADHD.
- Young people may have to return to the sole care of their General Practitioner (GP), and GPs may not be able to prescribe without specialist support.
- This has been described as a "twilight zone" gap in care.
- Studies have found a lack of understanding and knowledge from professionals and the public about ADHD in general, and specifically about ADHD in 18-25-year-olds.

If the young person does not experience a smooth transition to an adult service that meets their needs, there can be impacts on their health, education, and wellbeing. Some young people with ADHD may disengage and be at risk of substance misuse or other risky behaviours.

Only one previous study has directly asked young people with ADHD about their experiences of transition. We need to better understand young people's perspectives on transition to design a process that works for them and ultimately to improve their psychological, social, educational and occupational outcomes.

WHAT DID PARTICIPANTS TELL US?

We found four main themes in what the young people told us. These are shown in the panel above along with relevant direct quotes which illustrate the theme.

Some of what our participants talked about was similar to the findings of other research with young people with other mental health problems. However, the interviews also highlighted some new aspects.

Most young people discussed their relationship with their GP and the role of primary care. Understandably, some young people compared the closer relationship they had with their psychiatrist or paediatrician with the fact that they ‘never saw’ their GP. Participants expressed little confidence in their GP’s ability to help them manage their medication after leaving child services.

Medication was important to many of the young people interviewed. They made a strong link between medication and education. A major anxiety expressed by some participants appeared to be the fear that if their medication was stopped after leaving child services, their training and education might consequently suffer.

Most young people interviewed felt very unprepared for transition, and some felt ‘dropped’. They recognised the need to take more control over their ADHD as they moved into adulthood, for example by ordering their own medication. However, they thought that improved support and information would help them to do this. Young people in our study thought that transition at the age of 21 or older might better suit their needs and improve the continuity of their care.

WHAT MIGHT OUR FINDINGS MEAN?

This study presents the experiences of a small number of young people at a specific point in time. However, carrying out this research highlighted some important points for those planning and delivering services for young people as well as for future studies:

- Participants’ stories suggest that best practice around transition is not always being followed for those with ADHD. A gap between policy and practice was also evident in recent mapping surveys of healthcare professionals and mental health trusts in England.
- The need to prepare young people for transition is well recognised; however, our participants felt poorly prepared and wanted more information earlier on in the process.
- Extended youth services could provide more integrated social, vocational and mental health support during this time when they are more likely to disengage from sources of help.
- In our study, some young people were under the sole care of their GP where there was no adult ADHD service available; we know that this is the case in many areas of the country. GPs may need to be better supported in managing young people with ADHD; and future research should address how best to provide this.
- Key points of learning about the challenges of recruiting ‘hard to reach’ young people include the need to allow sufficient time for recruitment as well as flexibility in contacting young people to take account of their anxieties and preferences.
- This learning has contributed to a larger study aiming to follow up young people in transition across the UK: ‘Children and Adolescents with Attention Deficit Hyperactivity Disorder (ADHD) in transition from children’s services to adult services (CATCH-U)’.