



The experiences of healthcare transitions between child and adult services for young people with attention deficit hyperactivity disorder: a review of evidence

By Anna Price

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Attention deficit hyperactivity disorder (ADHD) is characterised by hyperactivity, inattention and impulsivity. It affects around 5% of children, and can be a long term condition, with research showing that up to two thirds of young people with ADHD will continue to experience symptoms into adulthood. However, many young people with ongoing healthcare needs do not make the necessary transition from child to adult mental health services.

Due to the way mental health services are organised in the UK, the move between services takes place for most young people between the ages of 16 and 18 years. This is a vulnerable stage in young people's lives when many other challenging transitions such as moving educational setting, moving out of home, or starting work are likely to be taking place. This change can be particularly challenging for young people with ADHD because the symptoms of impulsivity, inattention and hyperactivity make managing change difficult.

It is important to improve transition outcomes for young people with ADHD so that they continue to receive the treatment and support that they need. However, little is known about how healthcare transition is experienced by those involved.

Our research team completed a systematic review of qualitative research in order to increase understanding about experiences of transitioning into adult healthcare services for this group. Following a search of five main academic databases, we identified over a thousand articles which potentially contained related research. After screening for relevance, eight studies were included in this review. These were mainly based in the UK, and included reports of transition experiences from clinicians, people with ADHD, and parent/carers. The included studies were assessed for the quality of the research methods used and quality of reporting, with five studies scored as 'good' and three as 'poor'.

An analysis of the data was conducted, leading to five key themes that centred on the following:

- difficulties in transitioning
- hurdles that had to be negotiated in order to transition
- limitations of adult mental health services
- inadequate care
- the impact of transition difficulties

The review revealed that the lack of healthcare resource and provision for Adult ADHD in the UK had a direct impact on the availability and quality of care for young people with ADHD, leaving them feeling abandoned and unsure how to manage the problems they experience.

“There are places you can go as a kid, but not as an adult, it’s kind of swept under the carpet as soon as you reach 18” (Young Person) (Matheson et al., 2013)

The review also identified differences in thresholds between child and adult mental health services – and how bad problems had to be in order to be seen for treatment - which left some young people unable to access adult ADHD services. Parents and carers reported wanting to continue to be involved when the young person transitions, which was often difficult once the young person was in adult care. There was a lack of key information available for young people, such as where adult care services are located, and how to access them.

“A bit vague what’s available”(Nurse, CAMHS) (Belling et al., 2014)

“When she gets to 18 is there gonna be somebody there that can talk to us and talk to her? . . . We just don’t know. And it worries you” (Parent) (Swift, Hall, et al., 2013)

The transition process was reported as complex and unsupported, often leaving young people without the care they needed.

“A common experience of our patients is that once they reach 17, 18, they finish with Child Psychiatry and GPs stop prescribing without any preparation, . . . for some of them they experience that as quite traumatic because suddenly they couldn’t take medication” (Clinician) (Wong et al., 2009)

These transition experiences combined with the difficulties that individuals with ADHD are already likely to face, had a negative impact on young people at a time when they were already likely to be struggling to adapt to the increased demands of adolescence and young adulthood.

Our review findings demonstrate a clear need to better serve the healthcare needs of young people with ADHD.

ADHD has evidence based treatments available and it is very costly for the young person, their family and their community when they can no longer access treatment. At the moment, lack of supported transition means that too many young people are losing contact with services at a time in their lives when they need support the most. Only limited research was available, and more quality data is needed into healthcare transition experiences including accounts from carers and clinicians. We recently finished a three year research project focussing on experiences of transition, and our findings will be available soon. Please see links below, or visit the CATCh-uS website (<http://medicine.exeter.ac.uk/catchus/>) for details.

Implications for policy and practice:

- NICE guidelines on transition from child to adult healthcare services must be followed to ensure young people with ADHD are able to access adult services.
- The 2018 update to the NICE guidelines on diagnosis and management of ADHD, which includes a new section on *information and support*, ties in with findings from this review: providing young people and their carers with adequate information about what to expect during transition and in adult services is a crucial element of care.
- The current organisational split between child and adult mental health services poses additional challenges for young people with ADHD, because of difficulties with managing change. Therefore, more work is needed to understand and support their needs at transition.

Informational resource:

Since this review was conducted, a map of adult ADHD services has been created, as part of the National Institute for Health Research (NIHR) funded University of Exeter **CATCh-uS** project. This project focuses on what happens to young people with ADHD when they are too old to stay within children’s services. This map has been adopted by the **UK Adult ADHD Network** (UK-AAN) to share information on where services are available for adults with ADHD in the UK. It is available here: <https://www.ukaan.org/adult-adhd-service-map>

For more details, see here: <https://www.acamh.org/blog/adhd-service-map/>

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