

Transition to adult services and adulthood for young people with autistic spectrum conditions

Many young adults with autistic spectrum conditions (ASC) fail to achieve their potential outcomes in the early years after leaving full-time education. Access to transition support and appropriate services within the adult sector are key issues. This study explored ways in which young people with ASC (including those with high functioning autism and Asperger's syndrome) are supported over the transition period and into young adulthood. It also sought to understand and describe the experiences of young adults and their parents during this period.



Key findings

- Some localities had developed systems which ensured all young people with a diagnosis of ASC were supported in preparing for and planning leaving school.
- College careers could be foreshortened because mainstream colleges struggled to support young people with ASC, particularly managing behavioural issues.
- Young people and their families lacked autism-specific advice and support as they anticipated leaving further education.
- The absence of any meaningful daytime occupation, and the increased vulnerabilities associated with greater independence, were enormous worries for parents.
- A lack of appropriate employment opportunities and insufficient (specialist) support to gain and maintain employment, were key barriers to paid work.
- Young adults endorsed the benefits of autism-specific, preventive or 'low intensity' support. Peer support opportunities were highly valued.
- Parents found themselves, often reluctantly, assuming a key-worker role. They felt unskilled and uninformed in this role.

Background

Many people with ASC fail to achieve the so-called markers of adulthood such as employment, independent living, fulfilling social lives and 'adult' relationships. Improving outcomes for adults with ASC is a key objective for the Government (Autism Act, 2009; Autism Strategy, 2010).

Services and support available to individuals during the 'transition years', when young people leave school and lose access to children's services, will influence outcomes in adult life. There have been concerns that young people with a diagnosis of autism but with no learning difficulties (that is, those with 'high functioning autism' (HFA) or Asperger's syndrome (AS)) whilst not eligible for support from adult social care, do have significant support needs to enable them to successfully transition into adulthood.

Key aims of the study were:

- To investigate the ways in which statutory services provided transition support to young people with ASC, including those outside of special educational needs (SEN) transition arrangements and/or not known to disabled children's teams.
- To explore young people's and parents' experiences of planning for leaving school, the transfer from children's to adults' services, and life, and support needs, as a young adult with ASC.

Findings

The transition pathways and planning for leaving school

Some research sites had systems and structures in place which sought to ensure all young people with a diagnosis of ASC were receiving some sort of support during transition.

However, in other sites young people with HFA and AS were not eligible for support from transition teams and were leaving school with no ASC-specific input or support.

The lack of post-school options and, for those ineligible for adult social care, the lack of support, was the issue of greatest concern to parents and practitioners.

Experiences of further education

The accounts of college life of many of the young people we interviewed revealed it to be a more positive experience than school. However, parents and practitioners believed that college careers could be foreshortened because mainstream colleges struggled to support young people with ASC, particularly in terms of managing behavioural issues.

When it comes to the Asperger's part, no one knows anything about it until you've got it. And for people to sit there at colleges and stuff, to sit there and say, 'I understand what you're going through', yeah, you just want to turn round and smack them in the face, cos you know, they don't know... (Young adult with ASC)

Planning for leaving college

Young people and their families lacked autism-specific advice and support as they anticipated leaving further education. Young people who left college prematurely (either through suspension or dropping out) were identified as a highly vulnerable group. The circumstances of their departure precluded any advice or planning around next steps, and if ineligible for support from statutory adult social care, they were invisible to statutory services.

The lack of post-education options

The absence of any meaningful daytime occupation was an enormous worry for parents.

The consequences of not providing adequate support, or the lack of appropriate services or opportunities, were vividly demonstrated in this study. Some parents had little hope when speaking of their child's future, seeing instead a continued lack of meaningful daytime occupation, social isolation, mental health problems and dependency on the family.

I've got visions of him being on the dole for years and years and years....can't get an apprenticeship, can't get a job 'cos he's got special needs and people are going to take able-bodied first. He'll be fed up, upset, his self-esteem will go through the floor again. I won't even be able to get him out of his bedroom... (Parent)

Experiences of employment for young people and young adults with HFA and AS

Interviewees agreed that a lack of appropriate employment opportunities, and insufficient support to gain and maintain employment, were key barriers to paid work. Voluntary work was frequently identified both as a route into paid employment, as well as being a positive and meaningful day-time activity. Many wanted the opportunity to do some form of unpaid work.

Policies and practice with respect to supporting young people with ASC into employment appeared to be specific to localities. Transition teams did not appear to view employment as an outcome in which they actively engaged. The perceived (and actual) role of the Connexions service varied considerably between sites.

There were examples of positive practice from ASC-specific services supporting young people into work. However, there was also evidence to suggest there may be a lack of understanding of ASC among Job Centre and Job Centre Plus staff.

Support for young adults with HFA and AS

Community mental health teams and, in some places, specialist 'Asperger's teams', were identified as the first port of call for young adults with HFA or AS. All these services provided multi-disciplinary, but time-limited, support.

The other main providers of support for young adults with HFA and AS were third sector organisations, all of which were autism specific. These outreach services were, typically, very positively endorsed by young adults and parents. Some of the young adults we interviewed were very clear that they preferred spending time in such settings which they saw as 'normalising' them. However, knowledge of and access to such support was extremely variable.

Moving from the family home and independent living

The consistent view of interviewees was that, for many young adults with ASC, moving into an independent living situation was not appropriate or feasible in the early years of adulthood.

Cos I'm not sure I'm ready to, to stand on my own two feet yet, cos once you leave the nest, it's basically you versus the world and if you're not ready, it's gonna all come up to you and overwhelm you. (Young adult)

However, there was agreement that 'work' to support and enable the young adult to achieve this was required.

Parents reported particularly struggling with knowing how best to support their adult son or daughter to acquire independent living skills. This was a key area of unmet need for parents of young adults with HFA and AS who were not eligible for adult social care.

... we find it quite hard to strike the balance in trying to get him to be independent but also being able to do stuff that he can achieve and not be outside of his comfort zone, and, and I think that's where we might need guidance ... when looking for jobs to say well maybe not that, but this one might be good. (Parent)

The role of parents

A recurrent theme emerging from the interviews was that parents appeared to be very involved in supporting and, in cases, 'managing' their son or daughter's life.

We've had no help whatsoever from any other outside agency, it's just been my Mum helping me out. She's done a brilliant job as well but some help from another agency would have been great. (Young adult)

The accounts of the young adults we interviewed suggest that high levels of parental involvement in their lives were not, typically, unwanted. However, this was not a role parents usually wanted to assume.

He's now an adult with Asperger's not a child with Asperger's (laughs) and it was that realisation that, you know, just getting him through school wasn't the end of it, and it never will be the end of it... (Parent)

Implications

This study re-confirms the need to address the support needs of young people and young adults with ASC and their parents/carers. It also provides evidence which can inform and support the change and developments in services required by the Autism Strategy and National Institute for Health and Clinical Excellence (NICE) guidelines.

- It demonstrated that service models can be developed which ensure continuity of support to all young people with ASC as they leave school and become young adults.

- It highlights the need to develop systems by which young people ineligible for support from children's services and without a statement of SEN, are 'visible' to local autism strategy groups and commissioners of adult statutory services.
- It reiterates the need for autism-specific services, delivered by autism-trained professionals.
- It describes the types of services valued and endorsed by young adults with HFA and Asperger's syndrome, including: opportunities to meet and spend time with others with the same diagnoses; help with facing, and planning for, adult life; and specialist, and on-going, employment support.
- Peer support was viewed very positively by many of the young adults we interviewed. It suggests that developing, and evaluating, such provision would be worthwhile.
- Voluntary work placements in settings where ASC was understood and accommodated were consistently viewed very positively by the young adults who participated in this study. Further consideration of the strategic and planned use of such placements, and their impact on longer-term outcomes, may be productive.
- Some parents found themselves acting as key-workers for their adult child. They typically felt unskilled and unsupported in this role, particularly in terms of encouraging their son or daughter to become more independent and to maintain positive mental health. Whilst greater direct support to young adults is clearly one solution, it remains that the majority of parents want to support and nurture their adult son or daughter. Addressing parents' support and information needs is therefore important.

Study Design and Methods

The project was located in five research sites. These were identified as localities which had multi-agency transition planning processes and systems in place and had actively developed ASC specific services. Data was collected between 2009-2011. This was a mixed-methods study. The key sources of evidence reported in this research summary were:

- interviews with managers and practitioners in the five research sites working in transition services or services which support young people and young adults with ASC, including both statutory and non-statutory agencies and organisations
- interviews with young adults (18 – 24 years) with High Functioning Autism and Asperger's syndrome
- interviews with parents/carers of young people with autistic spectrum conditions (aged 16 – 24 years).

Postal surveys of parents and young people with ASC were also conducted as part of this study. Any available data on costs of transition support services was also collected from the research sites. Findings from these elements of the study can be found in the full report.

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Further details about the study can be found on this web page: bit.ly/TranASC

The full report is: Beresford, B, Moran, N, Sloper, P, Cusworth, L, Mitchell, W, Spiers, G, Weston, K and Beecham, J. (2013) *Transition to Adult Services and Adulthood for Young People with Autistic Spectrum Conditions: Final Report*. Social Policy Research Unit, University of York, York. Also available to download from this web page: bit.ly/asctREP



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