

# Moving on up?

Negotiating the transition to adulthood for young people with autism

“I want to be a racing car driver.” Anna, 14

Only 15% of adults with autism are in full-time paid employment.<sup>1</sup>

49% of adults with autism still live at home with their parents.<sup>2</sup>

“I’d like to work as a librarian one day.” Christopher, 20

“My first priority, once I’ve got a degree, is to establish my job, my career.” Joshua, 16

70% of parents feel that their son or daughter would be unable to live independently without support.<sup>3</sup>

“I always had a dream of being a bit like David Attenborough.”

Ben, 11<sup>4</sup>

Young people with autism have dreams and aspirations like anyone else. They have things they like to do and things that they are good at. But for many young people with autism, their dreams fall by the wayside and their potential lies unrealised as they face the grim reality of trying to access services and support as they reach adulthood.

make school  
make sense

Autism<sup>5</sup>, including Asperger syndrome, is a lifelong developmental disability that affects the way a person communicates and relates to people around them. People with autism experience difficulties with social interaction, social communication and social imagination – known as the ‘triad of impairments’.<sup>6</sup> Latest research suggests that around 1 in 100 children and young people has some form of autism.<sup>7</sup>

## Autism and becoming an adult

Most young people look forward to leaving school and starting the next phase of their life with great excitement. However, the transition from school to adulthood can be a particularly difficult time for young people with autism. People with autism struggle to make sense of, and communicate with, the world around them. In order to cope they tend to rely on structure, routine and rules to help them manage what can feel like an overwhelming mass of sounds, events and information. Disruption to these routines or rules can lead to high levels of anxiety and distress.

People with autism find social situations difficult and may struggle to make new friends. Individuals may find it difficult to adapt the ‘rules’ they have learnt in one context to new relationships and situations. They may also become distressed when other people break their rules or make it difficult for them to follow a familiar set routine. Consequently, people with autism may need to undertake a lot of preparation and planning to help them cope with even minor changes. Where a change as significant as leaving school is concerned, the need for effective preparation and planning is even greater.

Young people with autism will have become familiar with their school environment and may be used to receiving support there in a certain way. Moving to a new environment, often with less structure and reduced or different forms of support, will take getting used to, and having to build new relationships can be a frightening prospect.

Some young people will have complex needs which require very specialised support and placements but, whatever the level of need, people with autism will need to be prepared for any change to make sure that it happens smoothly and results in positive outcomes. It can be very hard for young people with autism to take in several options at one time, and it is therefore good practice to introduce options gradually.

People with autism also find it difficult to visualise life beyond their usual routine and to think in abstract terms about, for example, what they would like to do in the future, or how they might go about achieving this. This means they may be less prepared than most for their move into adulthood. The prospect of a new, uncertain world can be terrifying.

A new report for the Government’s Social Exclusion Unit has recognised that people with autism are more likely to experience social exclusion than other people.<sup>8</sup> The Treasury has recently announced £19 million for a Transition Support Programme for young disabled people.<sup>9</sup> It is essential that this programme meets the needs of young people with autism, who are more likely than most to experience difficulties as they make the transition to adulthood.

“ A specialist key worker who worked between children’s and adult services would have been brilliant. But the key worker has to be someone who understands autistic spectrum disorder. Being given so many choices can be stressful. She needed someone who understood that she needed to be given limited choices. ”  
Parent

## Planning for the future

With the right support, young people with autism can make the transition to adulthood successfully. Effective support and early planning around transition is essential to help them achieve their ambitions and realise their potential.

Young people with more complex needs should receive support at school through a statement of special educational need (SEN), following a thorough assessment of their needs. According to the *SEN code of practice*<sup>10</sup>, transition planning should start for young people with a statement at the age of 14, at their annual review, and involve social services, health and other agencies – such as housing – as appropriate. But the reality can be very different.

Only half (53%) of young people who have statements were issued with transition plans during the course of their education, falling to just one third of students in mainstream schools.<sup>11</sup> Of those who did experience transition planning, 45% were dissatisfied with the process. When planning and support is not effective, the transition process can become more stressful for young people and their families.

The *SEN code of practice* states that young people without a statement should have access to support and advice, but there is no legal requirement for a transition review or planning to take place. This can leave many young people and their families having to make arrangements for transition without adequate planning support from relevant agencies. Many local authorities are trying to reduce their reliance on the use of statements to support children with special educational needs. An unintended consequence of this is that pupils who may previously have received support automatically as part of their statement may now struggle to access transition planning and support.

“ I gave up a demanding job for a more flexible one in order to be able to provide more home support in the evening. I have had to become an expert in ASD [autistic spectrum disorders] in order to advise his teachers. I have had to research post-16 options and arrange Connexions contact as the school was not aware of the need for careful, forward-thinking transition planning – or of options suitable for him at college. ” Parent

At present there is a real lack of co-ordination in transition: only one quarter of parents feel that the support offered during their child's transition planning is co-ordinated. The Connexions service is responsible for overseeing the transition process for pupils with statements<sup>12</sup>, and Connexions personal advisors should provide information, counselling and support to help young people and their parents to identify the most suitable provision. Yet one in three parents does not feel that Connexions' knowledge of autism is adequate. Too often it is parents' understanding of the process and their personal resources which determine the efficacy of the transition plan.

The Government's National Service Framework for children<sup>13</sup> states that local authorities and health trusts should ensure that there is a multi-agency transition group in place to oversee transition arrangements. The National Autistic Society (NAS) would like to see this recommendation implemented as a matter of priority.

## A person-centred approach

All young people have the right to be involved in decisions about their future. This is clearly stressed in Government guidance and policy.<sup>14</sup> Very often preparation and ongoing work will need to be undertaken to enable the young person to understand what transition means and what options are available to them. Autism is a spectrum condition and people with autism need very individual support and individually-tailored opportunities.<sup>15</sup> They may also need different levels of support to understand choices and express their views in meaningful

ways, so that they can participate in the transition planning process. They may need help to visualise choices, which can be offered by using pictures, photographs and visits to help the individual understand and become familiar with a new environment. Some may need support with communication using tools such as the Picture Exchange Communication System (PECS) or Makaton.

According to our research, not enough is done at present to allow the views of young people to be heard in the transition process. Only 43% of parents of more able young people with autism felt that their child had been supported to express their views as part of the planning process, and for pupils who were less able this fell to just 20%.

“ At my son’s first transition meeting with the annual review, the very first meeting, he wasn’t even invited to the meeting...under the box for Trystan’s comments with the follow-on report there were no comments obtained from Trystan. And looking back at that I think it was quite disappointing that it was planning for my son’s future which didn’t involve any input at all from him. He has communication difficulties but he is able to express opinions on things and I think that should have been taken into account. ” Parent

“ I was put off by my careers advisor. I’d be telling her my ideas about what I want to do when I grow up, working at home doing art. She said, ‘Well, it’s very hard for someone with your problem.’ Well, if you’d seen my work you’d see that my ‘problem’, my autism, is what makes me good at art in the first place. She’d never, ever seen my work but she kind of put me off having a career. So I don’t know what to do. ” Eleanor, 16

Person-centred approaches aim to create and offer services that meet the individual needs and aspirations of young people with autism – as opposed to matching young people to services on the basis of availability. They provide a useful framework for involving not just the person with autism but also their family and wider support network. The input of family and other significant people, such as advocates who help young people with autism to express their views, can be invaluable in building up a picture of the support needed by an individual to achieve their aspirations. The transition process should be person-centred, taking into account the wishes of the individual and their family. Putting together individual packages of support like this will take time and effort, but in the long term placements are more likely to succeed.

## Moving on

Young people with autism often find it difficult to access appropriate placements when they leave school – whether they are intending to study, work or undertake training. They may also need help with housing options: seven out of ten parents believe that their children will need support to live independently after school, no matter where they are on the autistic spectrum.<sup>16</sup> For some people this will mean supported living in the community or residential placements. Yet the social care inspectorate recently described the process of moving to adult services as a ‘nightmare’<sup>17</sup>, and a Government report described it as like a ‘cliff-edge’<sup>18</sup> as the amount of support suddenly falls off as pupils leave school. Challenges can include a lack of suitable placements locally and late funding decisions by education and social services, which may cause placements to be lost or delayed. When young people are not able to access an appropriate placement, the experience can be very difficult and cause them anxiety and even mental health problems. Placements which are unsuitable are likely to fail.

“ We’ve not had much support during this transition process. We have had to look at nine alternative properties for our daughter but the social worker assigned to us only came with us to one of these. Our concern is that if she goes to an inappropriate placement she could cause harm to herself or others. She’ll run away. She can scale a six-foot fence no problem. We’ve been fighting full-time for nine months. There’s no alternative. Fighting is the only thing left for us to do. You sort of devote your life to it. ” Parent

### Support in post-16 education

Given the right support, many students with autism at college or university will go on to succeed. However, a committee of MPs recently concluded that post-16 provision is failing to meet the needs of young people with disabilities and special educational needs.<sup>19</sup> Many students with autism find it extremely difficult to obtain the right support to allow them to continue in further and higher education, and this can mean that they struggle, or even fail, when they get to college or university.

The support provided by a statement continues until the age of 18 if a pupil stays at their current school to attend the sixth form. However, for pupils who move onto further education, including sixth-form colleges, the statement will end two years earlier at 16.<sup>20</sup> Information on pupils’ needs is also often lost as they make this move. The NAS would like to see better joint working between schools, colleges and universities to ensure a smooth transition and good information sharing.

“ I don’t think I get enough support – I’d like more. It’s more like you go to the staff, they work with you. It’s good in one respect because you get to know a bunch of people, but it’s bad in another respect...if I’d stayed at the school I would still have it [one-to-one support], even in the sixth form. The agreement doesn’t go with you. And the lack of communication in the college – no one knows what’s going on. Like at school, even though we had our log books, they still told us when half-term was coming up and now we get told at the last minute, and we don’t get prepared for it, which is annoying. ” Eoin, 17

College and university tend to have a lot more unstructured time than school, which can be particularly difficult for students with autism. Although a student may be academically able, they may require additional support with the non-educational elements of their courses, such as organising their time, managing their finances, doing their grocery shopping or preparing meals if living away from home. Autism affects all areas of an individual’s life, but there is a lack of understanding of the breadth of need a young person with autism may have, which can make it difficult for them to thrive as they move to less structured environments after school.

Higher and further education providers need to consider social and independent living skills as part of any assessment of needs for young people with autism. According to our research, parents cite the lack of social skills programmes as the biggest single gap in support. 35% said this was the greatest area of need, particularly for more able children, including those with Asperger syndrome.<sup>21</sup>

“ One of the criteria that I’m going to be looking for from universities that I apply to will be what support they could offer me. There is no doubt that I will need support. In my lifetime I’d like to get married. My first priority, once I’ve got my degree, is to establish my job, establish my career, buy a house and hopefully concentrate on a relationship. ” Joshua, 16

### The London North Aimhigher Disability Programme

This programme was started in 2005 by the NAS Barnet branch in partnership with Aimhigher (London North Partnership). It provides learners aged 14-30 with autism and other disabilities, parents and relevant professionals from ten London boroughs, with information, advice and guidance on pathways to higher education, the support available and disabled rights in higher education. It also offers learners ‘transition schools’ that equip them with the skills and information they need to go on to degree-level study. The transition schools for autism are the first of their kind nationally.

Since 2005 the project has delivered 20 parents’ evenings and eleven three-day transition schools at Middlesex University, linking schools and colleges across the borough. It has also launched a Disabled Student Ambassador Scheme and a guide to higher education transition for students with Asperger syndrome or autism. The programme won in the ‘Voluntary Sector Organisation of the Year’ category at the London Education Partnership Awards 2007.

## The world of work

Work experience is a valuable tool for helping young people to gain a better understanding of the world of work. The opportunity to experience the world of work and try different types of activities and jobs is particularly important for young people with autism, who may find it difficult to visualise the workplace and need support to adjust to a different environment.

### The NAS Prospects Transitions project

Transitions works with forthcoming and recent graduates in the London area, providing pre-employment training and support, and working with them to find appropriate work placements.

James, 23, has a BA Honours degree in journalism. Through Transitions, he has received training in interview skills and techniques, assertiveness and confidence building. James has had work placements at the *Barking and Dagenham Post* and *The Independent*, where he learnt more about how the newspaper industry worked and developed an understanding of the pressures involved. James now has a more confident outlook on the rest of his life and attributes this to the help he has received from Transitions. At *The Independent*, James has been deputising for the sports editor and is about to start working for the newspaper full-time covering European and Premiership football.

However, it can be very difficult for young people with autism to access work placements and experience. Careers advisors and placement officers need to have a greater understanding of autism so that young people can access autism-specific support and appropriate placements.

“ My son did have some opportunity. He did a week’s work experience with his dad. I’m not sure if he’d have been able to do work experience if it wasn’t with his dad as there wouldn’t have been the support available. ” Parent

It is important to have a range of different types of employment programmes for people with more complex needs, so that they can access new opportunities and gain practical skills. The National Service Framework states that local agencies should develop strategies to widen education, training and employment opportunities for disabled young people.

Employment brings a range of financial, social and psychological benefits for employees. It also benefits the economy in terms of tax revenues, reduced benefits payments and greater productivity. But people with autism struggle to find appropriate employment. Latest research from the NAS shows that only 15% of people with autism are in full-time paid employment. Yet The National Autistic Society’s employment service, Prospects, was able to successfully place 67% of its clients in appropriate work environments in 2004. The total saving to the Government for all those clients who were employed was just under half a million pounds in less than three years.<sup>22</sup>

Such services are rare, and a lack of understanding among employers of how to make reasonable adjustments in the workplace for people with autism, as well as a lack of access to specialist employment support services, leaves too many people having to battle discrimination and cope with the challenges relating to their disability on their own.

**If transition fails, young people can find themselves embedded more firmly than ever in the family home, increasing stress on the family and resulting in more isolated lives. Making transition work benefits everyone. It's time for action.**

## Recommendations

### National Government should:

- through the new Transition Support Programme ensure that early and effective transition planning is in place for every young person with autism, whether they have a statement or not, including appropriate materials to support young people and their families through the process and autism training for key workers
- prioritise implementation of the National Service Framework actions on transition
- ensure that Connexions personal advisors receive training to support people with autism and that opportunities to develop specialisms are available<sup>23</sup>
- develop good practice guidance for post-16 education around supporting people with autism to meet their potential
- work with the Learning and Skills Council, the Higher Education Funding Council and other relevant organisations to ensure that further education providers are helped to develop support mechanisms for individuals with autism to access and continue their studies through study-based support and, most importantly, life skills support
- ensure that appropriate work experience opportunities are accessible to all young people with autism.

### Local authorities should:

- monitor the number of young people with autism who are reaching the age of transition to ensure effective planning of services and support during transition and into adult life
- ensure that young people with autism are supported to understand and take part in the transition process
- ensure that the transition process is person-centred, taking into account the wishes of the individual, as well as consulting with parents and an individual's wider social network
- work with primary care trusts and NHS trusts to develop multi-agency transition groups to oversee transition arrangements, as recommended in the National Service Framework, as a matter of priority
- develop local strategies in partnership with agencies to widen opportunities for education, training and employment for young people with autism, as recommended in the National Service Framework.

### Higher and further education institutions should:

- regularly review and develop the support they have in place for individuals with autism and produce a strategy to address gaps in support for students with autism
- work with schools to ensure good communication and a smooth transition for students with additional support needs
- ensure that all disability officers in post-16 education have specific training in autism.

“ If I could change one thing about my life it would have to be that I had been assessed then supported more during my teenage years. ”

Adult with Asperger syndrome

## References

- <sup>1</sup> New research carried out by The National Autistic Society in 2007 showed that 15% of adults with autism are in full-time paid employment.
- <sup>2</sup> Barnard, J. et al (2001). *Ignored or ineligible? The reality for adults with autism spectrum disorders*. London: The National Autistic Society.
- <sup>3</sup> Barnard, J. et al. Op cit.
- <sup>4</sup> All quotes in this report are from children with autism or their parents, unless otherwise stated.
- <sup>5</sup> We use the term 'autism' to refer to all autistic spectrum disorders, including Asperger syndrome and high-functioning autism.
- <sup>6</sup> Wing, L. and Gould, J. (1979). Severe impairments of social interaction and associated abnormalities in children: epidemiology and classification. *Journal of autism and developmental disorders*, Vol. 9(1), pp11-29.
- <sup>7</sup> Baird, G. et al (2006). Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). *The lancet*, 368, pp210-215.
- <sup>8</sup> Institute of Mental Health (2007). *Better outcomes for the most excluded*. Visit: [www.cabinetoffice.gov.uk/social\\_exclusion\\_task\\_force/documents/chronic\\_exclusion/better20070215.pdf](http://www.cabinetoffice.gov.uk/social_exclusion_task_force/documents/chronic_exclusion/better20070215.pdf)
- <sup>9</sup> HM Treasury and Department for Education and Skills (2007). *Aiming high for disabled children: better support for families*. London: HM Treasury.
- <sup>10</sup> Department for Education and Skills (2001). *Special educational needs code of practice*. London: Department for Education and Skills. Ref: DfES/581/2001.
- <sup>11</sup> In 2006 The National Autistic Society carried out the largest ever survey on autism and education as part of the *make school make sense* campaign. We received 1,400 responses from families, and we also interviewed 28 children with autism about their experiences. The statistics and quotes in this report are from that research, unless otherwise stated.
- <sup>12</sup> From April 2008 the responsibilities and funding for Connexions will be devolved to local authorities.
- <sup>13</sup> Department of Health and Department for Education and Skills (2004). *National service framework for children, young people and maternity services*. Standard 8: Disabled children and young people and those with complex health needs. London: Department of Health.
- <sup>14</sup> See for example the *SEN code of practice* (Department for Education and Skills, 2001), the *National service framework for children, young people and maternity services* (Department of Health, 2004) and *Improving the life chances of disabled people* (Prime Minister's Strategy Unit, 2005).
- <sup>15</sup> Department of Health (2006). *Better services for people with an autistic spectrum disorder*. London: Department of Health.
- <sup>16</sup> Barnard, J. et al. Op cit.
- <sup>17</sup> Commission for Social Care Inspection (2007). *Growing up matters: better transition planning for young people with complex needs*. London: Commission for Social Care Inspection.
- <sup>18</sup> Prime Minister's Strategy Unit (2005). *Improving the life chances of disabled people*. Visit: [www.cabinetoffice.gov.uk/strategy/downloads/work\\_areas/disability/disability\\_report/pdf/disability.pdf](http://www.cabinetoffice.gov.uk/strategy/downloads/work_areas/disability/disability_report/pdf/disability.pdf)
- <sup>19</sup> House of Commons Education and Skills Select Committee (2006). *Special educational needs: third report of session 2005-06*. London: The Stationery Office.
- <sup>20</sup> This is because funding for further education comes from the Learning and Skills Council rather than the local authority.
- <sup>21</sup> Batten, A. et al (2006). *make school make sense*. London: The National Autistic Society.
- <sup>22</sup> Alcock, J. and Howlin, P. (2003). *An evaluation of Prospects Supported Employment Service for individuals with Asperger syndrome*. Report for the Department for Work and Pensions.
- <sup>23</sup> From April 2008 the responsibilities and funding for Connexions will be devolved to local authorities.

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Thank you to the parents and young people who took part in the survey from which many of the quotes and statistics in this report are taken.

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To find out more about the *make school make sense* campaign, call 020 7923 5799 (answerphone) or email [campaign@nas.org.uk](mailto:campaign@nas.org.uk)

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