

# The All-Party Parliamentary Group on Autism

## Inquiry into transition to adulthood for young people on the autism spectrum



Transition to adulthood can be particularly difficult for young people with autism. As a result of their disability, many find change difficult to cope with and there is frequently a lack of understanding of their autism and a dearth of provision to meet their needs.

This report outlines the key findings and recommendations of the Inquiry. Over 220 stakeholders, including people with autism, parents and professionals, submitted evidence to the Inquiry. Some had experienced good transitions from school to adulthood but, for the majority of young people, the transition had been less than ideal.

### Key findings – the experience of young people and their families

#### **Effective and timely planning**

Many young people with autism often find that planning for their futures does not happen.

Frequently, decisions about a young person's next placement are made only when they are approaching the end of their schooling or, worse still, after they have left school. In the vast majority of cases where transition planning is taking place, it is happening without the involvement of adult social services. Contributors stressed how vital it is to address this. A recurrent theme was the mental health problems which developed, in part, as a result of these failures.

#### **Realistic yet stretching expectations**

For more able young people with autism, there is often insufficient understanding about the level of support they will require in adult life. Yet, for others, expectations may be too low meaning poor outcomes become a self-fulfilling prophecy. Transition planning must explore all areas where support may be needed to ensure young people with autism can reach their full potential in adulthood, including employment, independent living skills, relationship counselling, and leisure activities.

#### **Effective joint working across services**

Despite clear expectations from central government, it is clear from the evidence that there is a real lack of effective inter-agency working at local level. Many contributors spoke about the nightmare of a process in which many agencies were involved but no agency was taking responsibility. They argued that one person should be identified to act as the point of contact for the young person and their family and the liaison for all other agencies involved throughout the transition process.

#### **Understanding of autism amongst professionals**

Another strong theme was the need for further training in autism for professionals involved in transition. This would give them an understanding of autism, what it means for a young person, and how it may impact on their experience of the transition process, as well as their need for support, independent living skills, social and friendship skills, and workplace culture.

#### **Accessible information for young people and their families**

Young people and their parents must be fully aware of the options available to them, yet this is not always the case. Services must have sufficient resources and understanding of autism to implement effective strategies to allow young people the opportunity to contribute to their transition planning in an informed way. Many also identified a need for independent advocacy, to support young people's involvement in their own transition planning.

## Appropriate funding

There was a plea that transition should be about the needs of the young person first and funding second, although within the context of a realistic understanding of funding levels. Many pointed out that varying criteria for adult services can lead to some young people being excluded from services.

## Conclusion

There have been a number of positive developments in the field of transition, such as the Transition Support Programme, and there are pockets of good practice. Yet this Inquiry has shown that, for many young people with autism, transition is not working. Poor transition creates a chasm between the aspirations of young people with autism and the reality experienced by many adults on the autism spectrum, with serious repercussions for the individual, their families, and for public expenditure. This reports seeks recognition of the need to address this.

## What needs to change?

### Key recommendations for Government

- Guidance should require Directors of Children's Services to maintain a database of the numbers of children with autism in their area and share this information with adult services.
- Guidance should require Directors of Children's Services and Directors of Adult Social Services to review and plan services for young people with autism on a regular basis, including those children with complex needs in out-of-authority placements.
- The Government should extend the duty on local authorities to ensure that a multi-agency, person-centred transition plan is developed for each pupil with autism, beyond those with a statement of SEN from the age of 14 to those who receive support at School Action Plus.
- The disabled children's services national indicator (NI54) should be extended and young people's views gathered in a survey so that there is a specific focus on transition against which local areas can be measured.
- The Government's learning disability employment strategy should address the needs of young adults with autism in line with Public Service Agreement 16.
- The Department for Work and Pensions should ensure that Connexions provide information to all young people with autism on Employment Support Allowance and Disability Living Allowance.

### Key recommendations for Local Authorities

- All transition plans should be person-centred and include an assessment of the young person's social skills and identify training needs in this area.
- Connexions should monitor outcomes for all young people with autism and support all young people with autism up to the age of 24.
- Local authorities should ensure that all professionals who support young people with autism through transition have basic training in autism, including Connexions personal advisors.
- Local authorities should ensure that all young people with autism who require a transition plan are allocated a transition key worker trained in autism to oversee the process and ensure that the views of the young person and their family are at the centre.
- Young people with autism should be involved in decisions about their future. Where necessary, appropriate support should be put in place to enable them to communicate their views.
- Families should be included in planning for their son or daughter's future and be provided with appropriate and timely information to enable them to do so, as an equal partner.
- Primary Care Trusts should put in place protocols for transferring clinical mental health care for those young people with autism in Child and Adolescent Mental Health Services.

### For further information on the APPGA, please contact:

APPGA, c/oThe National Autistic Society, 393 City Road, London EC1V 1NG

Tel: 020 7923 5722 Email: [appga@nas.org.uk](mailto:appga@nas.org.uk) Website: [www.autism.org.uk/appga](http://www.autism.org.uk/appga)

Published by The National Autistic Society

© APPGA 2009