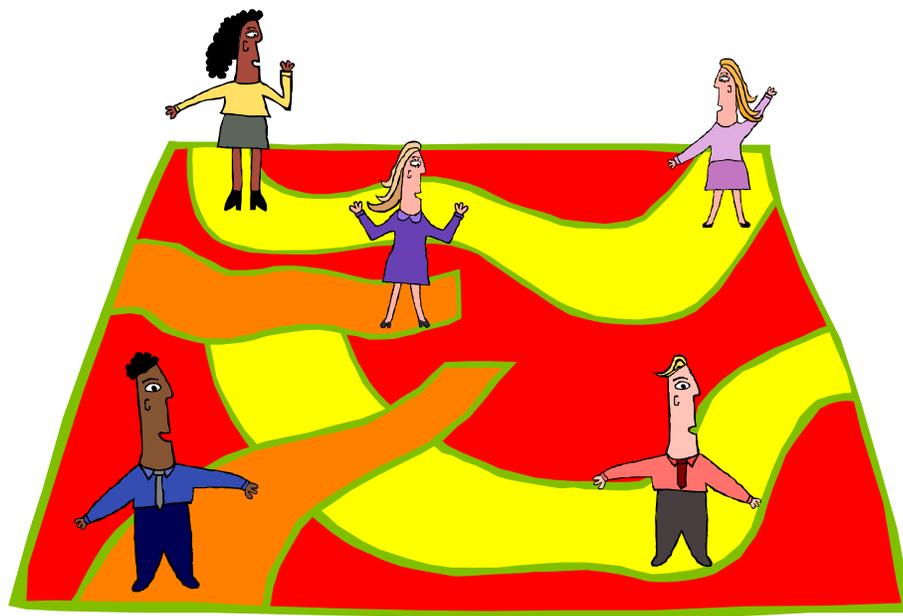


# Transitions and young people with Autism Spectrum Disorders: Executive Summary



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## **Background**

The project was instigated by the former Eastern Health and Social Services Board and commissioned in association with the Belfast Health & Social Care Trust, the South-Eastern HSC Trust alongside the two respective Education and Library Boards (Belfast and South-Eastern ELBs). The rationale was to help these organisations plan for young people who may need support on leaving school due to their special needs arising from Autism Spectrum Disorders (ASD).

The project aimed to find out:

- The numbers of young people aged 14 years and over who were currently in receipt of support services for pupils with ASD within education.
- The supports which the young people and their families currently receive from health and social services and the supports they feel they require now and once their son or daughter leaves school.
- To obtain the opinion of families and professionals about how the needs of these young people can best be met after school.
- To discover the young people's aspirations and hopes for the future.

Information was sought from four sources.

### **1. Number of pupils known to the two ELBs.**

- Around one in 100 pupils within post-primary are considered to have an ASD, although not all will have been formally diagnosed as such. This makes it one of the most frequently identified 'special needs' in childhood.
- The numbers of children identified by the two ELBs in Northern Ireland is in line with recent data on prevalence rates of ASD reported in the London area.
- The numbers attending post-primary schools will continue to rise for at least another two to five years; depending on the pupils identified in primary schools. This is monitored by the two ELBs.
- Over two-thirds of the pupils are educated within mainstream schools with over one quarter in Grammar schools for which academic selection operates.
- The data available on these ELB records gives little indication of the extent of the young people's difficulties, some of whom may be quite mildly affected. At present no standard tool is used to assess the young people's characteristics although this is presently under discussion at the Regional Forum.

### **2. Parental Views**

A self-selected sample of 52 parents provided information through self-completion questionnaires and the main themes were validated at a meeting attended by 26 mothers and fathers.

- The sample consisted mainly of young people with Asperger's Syndrome. Their needs have not been well documented previously.
- Although a wide range of difficulties was reported, most centred around lack of friends, social relationships and communication, and in organising themselves. But parents also commented on the variety of talents their sons and daughters possessed.

- Most current supports come through education although health and social services had featured in the past. Future support services mentioned focused on career advice, social and sport activities, counseling and information services for parents.
- After school parents aspired to the young people attending Further Education and embarking on a career or obtaining paid work. Although some had undertaken work experience only very few were currently in any form of part-time work.
- Parents identified five areas in which support services would be needed: personal and social support to the young people, education, work, living independently and support for parents. Specific suggestions were made for new forms of support services.
- A few parents raised concerns around mental health issues. Stewart et al (2006) note the increased incidence of depression among young people with ASD and the difficulties in recognising this.
- The survey of parents may have under-represented the views and experiences of less articulate parents whose children may experience additional difficulties that are not represented in these findings. This could include anti-social behaviours and involvement with police and criminal justice as noted in other research (Cashin and Newman, 2009; Allan et al, 2008).
- Looked After Children (LAC) with ASD living away from their families are also not included in the study. Bebbington & Beecham (2007) reported that in an analysis of 2001 data of 'Children in Need' in English local authorities, 25% of children with autism known to social services were Looked After Children; a slightly higher proportion among other children with disabilities (22%) and of all children in need (19%).

### **3. The views of young people,**

In all 13 young people responded to an online questionnaire. These responses from a self-selected sample of a small group of young people with ASD may not be representative of the broader teenage population who have this condition but even so it is likely that they have raised some of the key issues that are important to them.

- School was generally a positive experience with relationships being better with teachers than with other pupils.
- The leisure time was filled with a range of pursuits outside and inside the home. Many noted they were happiest when with friends. But a proportion of teenagers seemed to have few if any friends.
- More mentioned getting a job on leaving school rather than continuing their education, with a variety of options noted that seemed to accord with their interests and abilities.
- Some of the young people were aware of their particular difficulties although this was not explored specifically with them.

In many aspects the responses suggest a well adjusted group of young people. Other research (e.g. Muller et al; 2008), admittedly with an older population of people with Asperger's, who were interviewed about their lives, reported a profound sense of isolation, difficulty initiating social interactions, challenges relating to communication, a longing for greater intimacy, a desire to contribute to one's community, and the effort they expended to develop greater social/self-awareness.

#### **4. The Views of Professionals**

Self-completion questionnaires were returned from 16 professionals across different agencies.

- A range of different personnel and agencies are involved with young people and their families during transition but these tend to come mainly from Education with limited involvement from Health and Social Services.
- The importance of careers advice was noted as was access to information about post-school options.
- Further education rather than employment seemed to occur for most young people with whom the respondents had contact. However some dropped out due to wrong choice of course and lack of support.
- A range of ideas were provided as to how Further Education provision could become more 'ASD friendly'. These mirror the successful support given to pupils with ASD in mainstream schools.
- Supports for employment were also noted although less details were given as to how these could be provided.
- The need for young people to be supported in making and sustaining friendships was stressed and various ideas were given for doing this.
- Improvements were suggested for Health and Social Care provision but mostly in topics to be addressed and in the style of working. Access to counseling and to mental health services was poor.

#### **Service developments and recommendations**

The final section of the report identifies areas of service development and makes recommendations for improvements. These were developed in consultation with the Steering and Operational Groups and will be further discussed at a Round Table meeting of interested stake-holders to be held on 10<sup>th</sup> November.

The recommendations are grouped into five themes that resonated from the various data gathered as well as those found in the international literature (This is reviewed in an Appendix to the main report).

##### *1. Improved provision in post-primary schools*

Although there had been significant improvements within educational provision latterly, some further improvements are necessary in order to ensure better supports are available to the young people and their families during transition.

##### *2. Further education and employment*

In recent years, major investments have been made in services for children with ASD by Education and by Health and Social Care. But as this data makes clear, a third Government Department – namely the Department of Employment and Learning - will need to make available increased resources to the post-school provision that it funds, to meet the needs of the increasing numbers of school-leavers with a label of ASD. This includes further education, careers advice and training for employment. Participants at the Round Table event identified this as the major priority in the short-term. There is a period of up to three years for preparatory work to be done by DEL and the FE Colleges prior to a large and sustained increase in the numbers of pupils leaving school who have had ASD supports.

### *3. Social Inclusion*

A third major theme to emerge from this research is the need for increased supports to further the young people's social inclusion: notably their lack of friendships and social skill deficits. Strategies to promote social inclusion need to commence in the early teens and be sustained after formal schooling. The community and voluntary sector are probably best placed to meet these needs, although the Youth Service of the Education and Library Boards could also have an important contribution to make through their network of registered groups.

### *4. Family support*

A fourth domain in which improvements could be made to present service provision is the advice and support that is available to families. In part this requires better co-ordination among existing services.

### *5. Health and Social Care Services*

There is limited evidence from this study that any major investment will be required by Health and Social Care in terms of the specialist (second or third tier) services that they provide to families and young people, such as medical, psychological, nursing or therapy services.

Nonetheless improvements to certain Health and Social Care services may be beneficial to young people with ASD but also to other children and teenagers encountering social and emotional difficulties. The most promising approach is to equip primary care staff such as GPs, school nurses, social workers to offer prompt and appropriate Tier 1 and Tier 2 support to the young person and the family as well as to teachers and pastoral care staff within schools. Suggestions for improvements to social services are also noted.

### **Integrated service planning and delivery**

Our informants were agreed on one over-riding priority for managing and improving the transition process, namely the creation of an integrated system for commissioning and delivering a holistic response to the needs of these young people and their families, rather than the fragmented approach that currently operates. At a minimum this means bringing together Education, Health & Social Services and DEL but also DSD (social security and housing), DCAL (leisure and recreation) and OFMDFM. The goal would be:

- A shared action plan for ASD provision across sectors.
- Resources to commission innovative services on a cross-sectoral basis.
- The development of an integrated training strategy in relation to ASD.
- The delivery to individuals of an integrated support package that extends into adulthood.

Suggestions for achieving this along with proposals for further research are noted.

### **Acknowledgements**

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## **Membership of Groups**

### **Steering Group**

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Bria Mongan, South-Eastern Health and Social Care Trust

Marian Robertson, South-Eastern Health and Social Care Trust

Miriam Somerville, Belfast Health and Social Care Trust

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### **Operations Group**

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