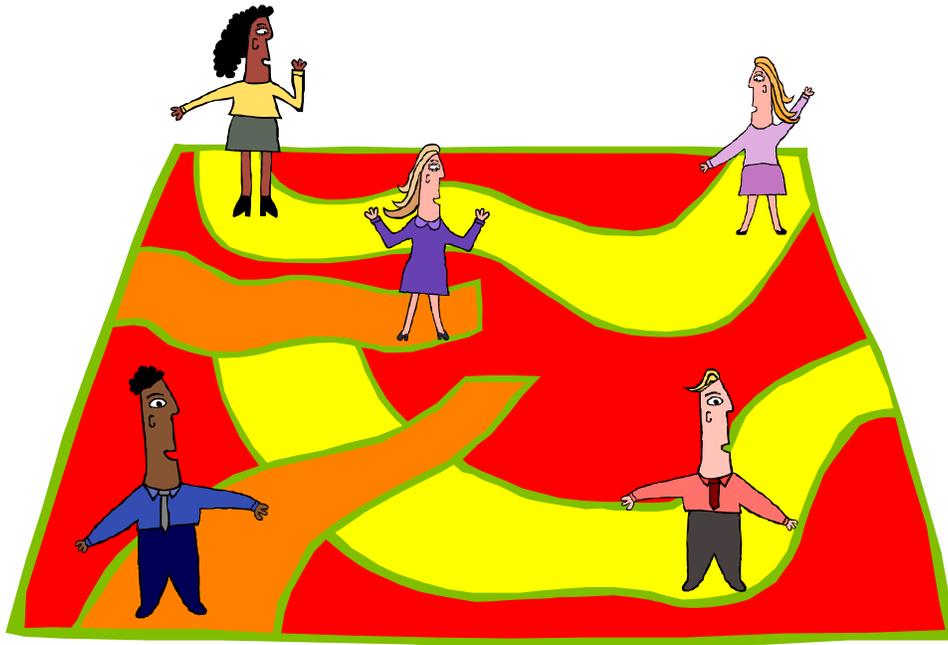# Transitions and young people with Autism Spectrum Disorders

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Contents

Executive Summary

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 question-aires 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 10th November.

The recommendations are grouped into five themes that resonated from the various data gathered as well as those found in the international literature (see Appendix 1).

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

Project aims and methods

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.

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.

Five strands of work were undertaken. Details of the methods used and a summary of the information gathered are given in the following sections.

- Section 1 provides details on the number of pupils known to the two ELBs.

- Section 2 summarises the main issues identified by a sample of 52 parents through self-completion questionnaires and validated at a meeting attended by 26 mothers and fathers.

- Section 3 presents the views of seven young people who responded to an online questionnaire.

- Section 4 outlines the views of 16 professionals involved with these children and families.

- Section 5 identifies areas of service development and makes recommendations for improvements. These arose from the findings reported in the previous sections and were developed in conjunction with the Steering and Operational groups established for the project. They were further validated at a round table meeting attended by 22 persons from a range of stake-holder agencies and groups. Suggestions for further research are also noted.

- An appendix summarises relevant legislation and findings from other research projects on the topics of transitions.

In all, over 100 persons have contributed their experiences and insights to the process. Although the information was gathered in one geographical area, the lessons are perhaps applicable throughout Northern Ireland.

Section 1: Pupils with ASD in post-primary school

This section provides details on 582 pupils in post-primary schools within the two Education and Library Boards in Northern Ireland. All the pupils either had a confirmed diagnosis of ASD or were deemed by ASD support staff to benefit from additional assistance based on their assessed characteristics. They were recorded on databases established by the Boards to record pupils with ASD.

Overall these pupils represent around 10 per 1,000 of the school population (10.4 per 1,000 BELB and 9.4 per 1,000 SEELB) which is in keeping with rates reported elsewhere in the UK (Baird et al, 2006). However it is very much higher than the rates known to autism services in the Lothian Region of Scotland of 33 per 10,000 (Harrison et al., 2006).

School placement

The numbers of children by type of school and ELB is given in Table 1.1.   The SEELB has proportionately more children attending secondary schools than the BELB and fewer in special schools. However this may represent an undercount of pupils in their special schools especially pupils who also have severe learning disabilities.   The proportion of pupils in Grammar schools - at around one quarter - is roughly comparable in the two Boards.

In terms of special schooling: 63 pupils (10.8%) were in SLD schools; 47 (8.1%) in MLD schools; 44 (7.6%) in schools for children with medical needs and 11 (1.9%) were EOTAS.

Table 1.1: The number of percentage of pupils by type of school in the two Boards

School Grouping	Numbers and Percentages	ELB supplying data		Total
		Belfast	**SEELB**	
Secondary	Number	106	150	**256**
	% within ELB supplying data	*33.1%*	*60.5%*	***45.1%***
Grammar	Number	89	58	**147**
	% within ELB supplying data	*27.8%*	*23.4%*	***25.9%***
Special	Number	125	40	**165**
	% within ELB supplying data	*39.1%*	*16.1%*	***29.0%***
Total		**320**	**248**	**568**

Other Boards

A number of children attend schools in the two Board areas but are resident in other Board areas as Table 1.2 shows. In addition there are 63 pupils in BELB schools who are resident in the SEELB area and 2 who attend schools in SEELB area but are resident in BELB area.

**Characteristics of the pupils**

Overall many more pupils are male (86%) than female (14%) and this is comparable across three types of schools and age groupings.

Table 1.2: The number and percentage of children by the Board area of their residence

Board area	Number	Percent
Missing data	5	.9
BELB	256	44.0
NEELB	14	2.4
SEELB	300	51.5
SELB	7	1.2
Total	582	100.0

The age bands of the pupils are shown in the Figure 1.1. In all 284 pupils (49%) are aged under 14 years and 298 are 14 years and over. Again the age distribution is similar across the three types of schools.

The numbers of pupils is higher for the younger age groups which reflects the increased ascertainment of pupils with ASD that has occurred in recent years, particularly in primary schools.
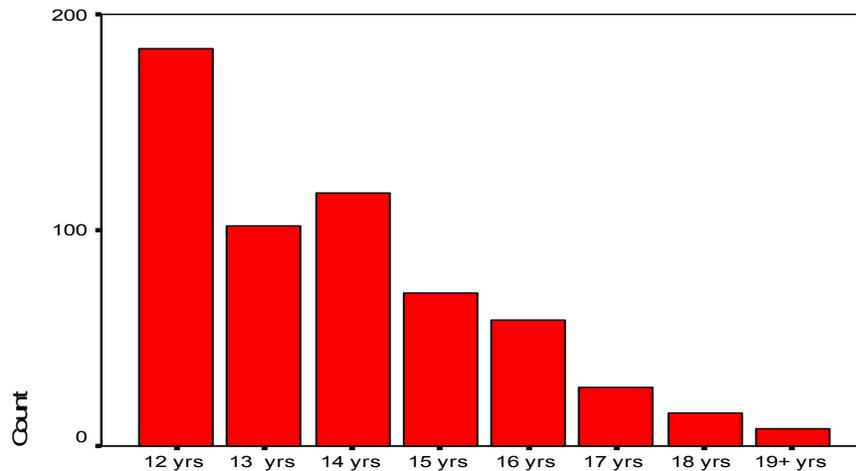
Figure 1.1: The number of pupils with ASD in each year group

Socio-economic status

The socio-economic status of the pupils can be estimated from deprivations rankings based on the postcode of their home address. In all 28.6% of pupils live in areas that are ranked among the 25% most deprived in NI whereas 36.9% are from the 25% least deprived.   This distribution varies significantly across the types of school as shown in the Table 1.3. Pupils attending Special Schools are more likely to live in more deprived areas whereas nearly half of those in Grammar schools come from the least deprived areas. This mirrors the distribution for all students and not just those with ASD.

Also those pupils aged under 14 years are more likely to come from areas of least deprivation (Chi Sq 6.1 p<0.05).

Table 1.3: The number and percentage of pupils grouped by areas of deprivation across the three types of schools

Deprivation groupings	Number and Percentage	Type of school			Total
		Secondary	**Grammar**	**Special**	
More deprived	Number	70	20	71	**161**
	% within school group	*27.7%*	*13.6%*	*43.6%*	***28.6%***
Middle	Count	90	56	48	**194**
	% within school group	*35.6%*	*38.1%*	*29.4%*	***34.5%***
Least deprived	Count	93	71	44	**208**
	% within school group	*36.8%*	*48.3%*	*27.0%*	***36.9%***
Totals		**253**	**147**	**163**	**563**

Health and Social Care Records

At present, there is no consistent recording of children and young people within the databases used by Health and Social Care Trusts, such as the Child Health System, L-CID and Soscare. Certain Trusts, prior to reorganisation, had maintained quasi-ASD registers mainly for children under 11 years. A study conducted for the Department of Education found wide variation in the number of preschool children known to the 11 community HSS Trusts with an overall prevalence of 57 per 10,000 (McConkey, Kelly and Cassidy, 2007). Hence, as in England and Scotland, it is likely that a smaller proportion of children with ASD are known to health and social care services (Bebbington & Beecham, 2007;Harrison et al., 2006).

Conclusions

- 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 still operates in Northern Ireland.

- 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.

Section 2: Parental Views

This section gives details on the sample of parents recruited to the study; the characteristics of their children and their difficulties; the services and supports they and the young people receive at present, and parental aspirations for the future and the supports needed to achieve these.

Sample

In seeking parental views, it was decided to limit the sample in the first instance to children in year group 10 and above (aged 14 years and over).   These are the young people in transition and for whom post-school options will be more pressing.

It was further decided to inform all parents in the two Boards who were resident in the Board area about the project although ELB staff did exercise their judgement in whether an invitation was sent to certain families because of ongoing difficulties (this happened in five instances). In all letters were sent by ELB officers to 281 parents/guardians.

Parents were invited to opt into the Project by returning a Freepost reply slip, or by emailing or telephoning their contact details. In all, 92 replies were received (32%) which was much lower than expected but may be an indication of a lack of concern on the part of some parents that they and their child will require any additional assistance after school. (NB For reasons of confidentiality we could not identify the respondents from non-respondents.)

Information Gathering from Parents

Parents were sent a letter describing the project along with a self-completion questionnaire although they had the option of giving this information by telephone interview and by completing it online. Parents were also asked to indicate their interest in attending a meeting and also an invitation and consent form was enclosed for their son or daughter's participation.

In all completed questionnaires were received from 52 parents (57% of those who indicated an interest in participating but only 19% of the eligible population).   Four questionnaires were completed electronically; the remainder in writing.

Hence the findings are unlikely to be representative of all the young people identified by ELBs and this needs to be borne in mind when reading this section. Nonetheless the issues raised by parents are likely to be ones that are relevant to other families.

Parental respondents

All the respondents were mothers;14 (28%) of whom were single parents. Most (80%) owned their home and 84% had children under 16 years at home. In 14% of household the parents were unemployed.

Characteristics of children of parental respondents

Of the 52 children, 85% were male and 15% female. School attendance was as follows: 18 (36%) Grammar; 13 (26% secondary schools), 11 (22%) special schools; 7 (14%) FE College and 1 attended another type of school (2%).   *(NB Compared to the population figures reported in Section 1, more respondents in this sample came from Grammar schools and fewer from secondary and special schools.)*

Of the 38 parents who declared a postcode: four (10%) lived in the top 10% most deprived areas and a further five (13%) in the 25% most deprived areas whereas 14 responses (37%) came from parents resident in the 25% least deprived area.

The mean age of the children in 2009 was 16 years (range 15-20).   Over one third (35%) were now aged 15 yrs; 29% were aged 16 years; 29% were aged 17 and 18 years; and 8% were aged 19 and 20 yrs.

The mean age at which the child had been diagnosed with ASD was 7.6 years (range 1 to 16 years). However the mean age was significantly lower for those attending special schools (mean 4.5 years) and highest for those in Grammar schools and FE Colleges (8.6 years).

Parents most commonly named their child's diagnosis as Asperger's syndrome (N=41: 79%) but of these 18 parents (35% of total) noted the pupil as having at least one other difficulty. These included: ADHD (N=9), dyspraxia (6), dyslexia (4), epilepsy (2), asthma (2) mobility problems (2) as well OCD, anxiety, auditory processing and bowel problems (each mentioned for one pupil.   In addition 5 parents noted that their child had either Autism or an ASD and another five noted associated learning difficulties (4 moderate: 1 severe). One parent reported the child as having a Pervasive Developmental Disorder.

In all 41 pupils (79%) had a statement of Special Educational Needs. The average length of time the statement had been in place as reported by parents was 8 years. However for two pupils the statement had been issued in 2009.   Of the 36 pupils of school age with SEN statements, parents reported that a 14+ transition plan was in place for 20 of them (56%).

Perceived difficulties

Parents were asked to rate their son or daughter on a listing of difficulties often experienced by young people with ASD. A four-point scale was provided: much less able (than other children of same age), less able, the same and more able. Table 2.1 summarises the percentage of parents rating each item (N=50 due to missing data). (NB The table has been re-ordered in terms of the items with the highest percentage of pupils rated as 'much less able').

As the shaded items in Table 2.1 show, nearly all the children were rated as being 'much or less able' in four aspects: friendships, joining in social activities, organising themselves and being anxious. Also communicating with other people and adapting to change were also common difficulties although not as marked as for the previous four.

On average, parents rated their child has being 'much less able' on six difficulties (range 0 to 16). This is indicative of the wide variation in the number and type of difficulties that children with ASD encounter.

Other difficulties mentioned by parents that were not included in the Table, were: concentration, low self-esteem, fearful of going out and mental health problems.

Parents were asked to nominate their child's greatest difficulty. Of the 48 responses, 81% mentioned socialising and communication. Some sample comments follow:

8. Lacks social skills of which she is fully aware; has no friends outside school; can't tell when she's being made fun of; must have quiet alone time during the day; easily upset

17 Social interaction; wants to have friends but as she gets older this is more difficult as peers are more mature

18 Persistent talking to a disinterested audience about the current topic of interest

25 Greatest difficulty is mixing with his peers, can find it difficult to understand their behaviour

35 Appropriate communication and effect on forming relationships, poor listening skills and difficulty reading social cues; leads to fallouts and stress

Table 2.1: The percentage of pupils rated by parents in terms of their perceived difficulties

Difficulty	Much less able	Less able	Same	More able
Having friends	58%	39%	4%	0%
Organising themselves	58%	32%	6%	4%
Joining in social activities	55%	39%	6%	0%
Anxiety, worry	54%	32%	8%	6%
Argumentative/aggressive/anger outbursts	45%	20%	20%	14%
School performance in writing	41%	33%	16%	10%
School performance in mathematics	41%	26%	18%	16%
Adapting to change	39%	58%	4%	0%
Clumsiness, poor coordination	39%	39%	18%	4%
Communication with other people	35%	61%	0%	4%
Knowledge of sex and relationships	31%	44%	21%	4%
Sleep disturbance/going to bed	29%	24%	41%	6%
Eating difficulties	26%	28%	45%	2%
School performance in reading	24%	35%	14%	28%
Sensory difficulties, e.g. to noise, light	23%	58%	17%	2%
Unusual mannerisms	19%	66%	13%	2%
Speech difficulties	14%	30%	40%	16%
Playing computer games	10%	12%	31%	48%

Adapting to change and requiring structure were mentioned by 13 parents (27%).

> *5. Lack of motivation; organisational skills-needs tasks broken down; needs continuous supervision in order to complete tasks; easily distracted*

> *30 Having to repeat for him things to do and he can become aggressive*

ASD treatments used by families

In all, six parents (12%) reported that they used a particular approach to help their child at home, including TEACCH (N=4), ABA (N=2) and Son Rise (N=1). One young person is taking the ADHD drugs Stratterra & Concerta (N=1). A further two parents commented that they had used TEACCH or ABA in the past.

Young people's talents

Parents were also asked to report on what they felt their children were good at: their strengths and interests. A wide range of talents were reported and these were grouped as follows: computers (N=20), sports activities (N=14), personal qualities (N=8), creativity and imagination (N=8), specialised knowledge on chosen subject (N=7), memory (N=5), musical (N=5), reading (N=4) and languages (N=4). Other topics mentioned were: cooking, debating, manual dexterity and school work. Sample quotes included:

1. Has a great imagination: if in the right frame of mind can produce excellent short stories. Has had two poems published. Loves anything with nature & has extensive knowledge of ancient Egypt and dinosaurs. Enjoys fishing trips.

10 Honest, caring, sensitive and kind; articulate; academically bright, helpful at home; special interest-Star Wars- other interests; Army Cadet Corps. Trumpet school band; conservation volunteers; involvement in church activities.

19 She has won public speaking competitions and poetry has been published since she was seven.. Excellent at all languages. Loves to write songs(lyrics and music).

31 Her passion/obsession is sports and sports statistics. Her enthusiasm for sport far outreaches her skill and can lead to a lot of frustration i.e. not getting picked for teams. Has great stamina and never misses any training sessions.

37 He loves rugby and boxing; is a member of Army Cadets and loves shooting; enjoys cooking or baking.

47 Sport, drama, dance, swimming but had to leave Belfast City Swimming Club as kids knew he was different because coach had to remind him of his strokes and how many lengths he had left.

48 Is a very tidy child who likes routine. Is a very caring child but very vulnerable and takes everything very seriously. He has a good sense of humour and has a hearty laugh.

Work experience

In all 22 (42%) of the young people had taken part in work experience placements as part of their school curriculum although six of these placements had been organised by families. Most coped well with them although three found it quite stressful or the placement had proved unsuitable. Parents commented as follows.

46. He coped but it was working in a local shop under the supervision of a close family member and he was unable to interact with customers

14. As he knew the man who worked there, he wasn't too bad and got a wonderful report back. He did however worry about doing things wrong.

28. Did not get on well. Found the social interaction and demands very difficult

39. She got on great because I went to see them to explain her diagnosis and what was the best way to assist her. It was in an art print workshop which she loved as it was meaningful to her future career

Only three of the young people currently have any form of employment (in office, chip shop and stables) and a further two people previously did have jobs but one was not able to sustain his work. Several parents commented that they or their son/daughter would like to have a job.

91 Colin did have a part time job over Christmas which provided him with the opportunity to enhance his social skills.

9. Full time office work obtained with help from job centre but only after I was proactive.

5. I would like to organise something but don't know how or how to approach employers.

The main obstacles that parents foresaw in their son or daughter getting or holding down a job after school were centred around problems in relating to other people (N=18), being successful at interviews (N=11); organizing and concentrating on their work (N=11); attitude of employers and co-workers (N=8); anxiety and lack of self-confidence (N=7); communication difficulties (N=6); getting qualifications and sufficient training (N=5) and travelling to workplace (N=3).

10. Having to go through an interview, working with others, having/maintaining self-confidence

14. His anxieties, communication skills, anger outbursts when he's frustrated. His inability to read facial expressions and body language

31. Lack of structure, support, understanding in the workplace. Prejudices and lack of understanding from colleagues

40. That he will not receive the appropriate training and people will give up on him because they don't understand

39. Anxiety levels and isolation; organising and managing her work load and social life as she doesn't know how to balance these; she has low self esteem and is always looking for perfection and pushes herself too hard. Requires continuous reassurance; employers not understanding her and the effects of having Aspergers, inflexibility of employers and other peer members of staff

Services and supports received

Parents were asked to indicate the supports they and their child had received in the past; those which they get at present and those that feel they need now or in the future. These showed a very different pattern of responses.

The three supports most commonly reported as having been received *in the past* were Speech and Language Therapy (62% mentioned), Occupational Therapy (54%) and clinical psychology/ASD service from HSC trust (37%).

The supports most commonly reported *at the present* were regular meetings with teachers to review progress (60%) and having a classroom assistant (46%). Other supports were 14+ transitions co-ordinator (29%) and ASD Advisory service from ELB (27%). Other supports were received by fewer than 25% of the families. Services from HSC Trusts were not widely reported: social worker (21%) Clinical psychology/ASD advisory service (21%), CAMH (12%) SLT (4%) and OT (4%). None of the families receive domiciliary services or respite breaks.

The supports perceived to be *needed now and in the future* were: careers and disability advisory service (40%), 14+ transitions coordinator (40%), sports and social activities at evenings and weekends (39%), counselling and advice service for the young people (37%), advice and information service for families (31%) and CAMH service (31%). Other HSC Trust services were rarely mentioned such as social workers (14%), SLTs (12%) and OT (12%) although more families did want behaviour supports teams/ASD advisory services (23%). Also 21% of parents desired help at home and 12% opportunity for respite breaks.

Post-school expectations and aspirations

Parents were specifically asked to select from four options the most likely post-school placement for their son or daughter. FE College (44%) followed by University (34%) were the most popular options with Vocational Training Centres (12%) and Day Centres (6%) also selected.

A range of responses were given to the open question about what they would like to see happen for their child after school. The most common responses were around having employment and a career (N=28) with mention also of undertaking further education (N=16) or appropriate training courses to qualify them for jobs (N=5). Other parents responded in terms of the young person achieving their ambitions and being happy (N=8), having friends (N=5) and living independently (N=5).

3. Continue for next 2-3 years in another Educational setting, hopefully lead to college then employment and independent living.

14. That he gets a job he's content with, with people who understand Aspergers.

23 Would like my child to feel fulfilled in employment which allows him to be independent and have a fairly "normal" life

25 He intends to apply for a place at Uni and is really looking forward to this. We have no idea of what support is available if any.

31 Would love to go to Uni. We are unsure of her ability to do this. Failing this to see some structured approach to career information and channelling her into something she likes and can cope with.

41 He will go to further education and get catering qualifications, will integrate into main stream youth activities.

94 I would like him to stay on to school for another year and also benefit from regular work experience and day release at college. I feel he needs to have his confidence increased and an extra year at school would achieve this.

Parents were then asked to name the supports they felt they and their son or daughter would need to make these hopes come true.   Figure 2.1 summarises the main themes to emerge from their responses. These were confirmed by 26 parents who attended a specially convened meeting to review the main findings and also to provide with information about topics of concern to them[1]. (Invitations had been sent to 29 families returning a questionnaire) who had indicated an interest in attending such a meeting).
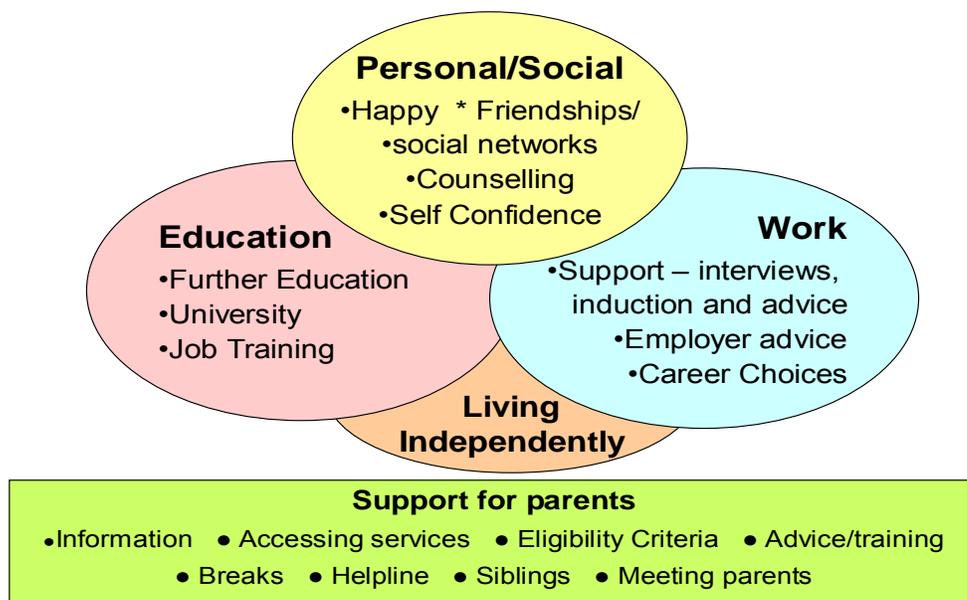
Figure 2.1 Main themes in parental responses about post-school supports

Future support services

At the consultation session, parents identified the support services that they would find helpful and suggested how existing services could be improved.

- *Special Educational Needs Co-ordinators* – a similar role would be needed in Further Education. Although information does not always filter down from them to other teaching staff.

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[1] Short presentations followed by question and answer sessions were provided by representatives from Belfast Metropolitan College, Orchardville Society and Disability Advisory Service of the Department of Employment and Learning.

- *Psychological services* – less staff turn-over would led to greater consistency; re-assessments and reviews are needed.

- *Social worker* – especially in relation to family supports. Child and Family services stop at 14 years.

- *Counselling and social skill training* – there is a big dearth at present.

- *Career and Educational Guidance* – delays are experienced in accessing this.

- *Befrienders and mentors* – to promote social activities.

- *Liaison workers to support employment and employers* – the Orchardville model seemed appropriate.

- *Mental health services* – including access to CBT.

- *Awareness raising about ASD with professionals and public* – such as FE Lecturers, police and public transport personnel.

Past experiences

Finally in their questionnaire replies and at the consultation meetings, parents took the opportunity to describe their disappointment and frustrations with existing services and their negative experiences of them. A recurring theme was the lack of support and parents having to fight to get the services they receive.

92 From what I can make out from parents of older teenagers who have left school, there appears to be absolutely no services at all for our young people and they are left totally isolated at home with little social contact, leading to problems with mental health and behavioural problems.

4 I have been very disappointed by the lack of support my son has received over the years. Anything in the way of support that we have got I have had to fight for. Much was promised but never received even with a statement of education.

16. Because of ignorance and prejudice I have had to fight every inch of the way to obtain services and help for my child. He has become depressed and suicidal because of others' attitude and their inability to accept his disability. He is socially vulnerable and isolated as there is no specialist help available

38 When the child is younger, they can be MADE to socialise a bit more i.e. summer schemes, but it becomes more difficult to make a teenager participate in things and after 12 or 13, there is not many activities (general) for them i.e. if they are not good at sports or music, there is not much else

46 I feel teachers should be taught to recognise these disorders.. in my experience my child was seen as having emotional problems and on more than one occasion it was implied that the problem was with my parenting ability and our social background i.e. divorced, single parent, not able to cope

44 I feel all statutory agencies need to become involved together in one body to give these children a complete package to enable them to move forward, regardless of their ability. These children have a great deal to offer and require help to do so, especially in areas of anxiety, depression and suicide attempts. Please help.

Conclusions

- The sample consisted mainly of young people with Asperger's Syndrome. Their needs have not been well documented previously.

- Their difficulties mostly centred around lack of friends, social relationships and communication; and in organizing themselves although a wide range of difficulties was

reported. 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%).

Section 3: The views of young people and professionals

Parents were asked to indicate when returning their questionnaire, if their son or daughter was willing to give their views, either by completing a questionnaire or by telephone interview. In all 26 young people (49% of parental returns) volunteered and were sent a personal letter explaining how they could access an on-line confidential questionnaire from a web page hosted by the University of Ulster. A reminder letter was also sent when schools resumed after the summer break.

In all, 13 responses were received: 50% of those who expressed interest but less than 5% of the young people in the study population. Other forms of obtaining information from the young people, such as interviews and focus groups were considered but they would have required more resources than were available to the study. Future studies might be devoted to listening to the young people at various stages; before and after leaving school.

The questionnaire covered these areas: self-perceptions, school, leisure time, after school, working and health.

A profile of the young people

The young people ranged in age from 14 to 19 years. Three attended a special school, three a grammar school, four secondary/integrated schools and one a Further Education College (two did not supply this information).

All but two were able to name at least one thing – often more- that people said they were good at, including academic subjects, sports and socializing.

> *I'm a good singer, I'm good at art and English and languages and creative stuff- I suppose I'd be quite academic if I actually cared about school. I am quite smart, though, but my social life matters more to me.*

> *In my opinion I am good at languages such as French & Spanish, ICT, Journalism, Geography. I am good at sports such as hockey & swimming.*

> *To quote my most recent English report, I have a "sophisticated vocabulary and an often striking turn of phrase." Beyond that, I have no idea.*

All could mention things they were not so good at or they found hard to do. A range of answers were again given with Maths, sciences, writing and spelling mentioned among the school subjects. Difficulties with communication and socialising were also noted.

> *I find it difficult to understand what is going on around me at times. I am not very good at organising myself at times. I find it difficult to play sports at times as well.*

> *I find it hard to make new friends but when I try I make a new friend*

> *I'm not very good in social situations. I write much more fluently than I speak, and I have a tendency to mutter and slur my speech. I also curse a lot.*

Reactions to school

Nearly all the young people noted something they liked about school but few mentioned school subjects. Rather the emphasis was on friends, sports and work placements. For two persons, the school holidays were the best thing!

> *I like sports and making friends and playing and talking to them*

> *We have a special club in year 11. I like my mates and playing football and cookery. We are going to tech this year- cool - we can wear our own clothes.*

What I like best about going to college is going to work experience. I go to Tesco's for work experience three days a week.

Most wrote good things about their teachers – at least some of them. Eight said they got on really well and for five they were 'OK'.

My teachers are brill. They are nice and don't shout too much. They look after you if you are sick

The teachers are ok and the other staff are friendly

Most of the teachers are ok, but some of the older teachers just throw you a book and do not explain how things are done.

Their relationships with fellow pupils did not seem to be so good. Only two mentioned they unambiguously that they got well with their friends, 'OK' was a more common answer and two persons noted they did not get on so well with others.

I get on fine. I talk to quite a few of them. They are quite friendly.

Mostly everyone gets along with me but there are some people who are mean to me

OK but usually I just like to play by myself.

I get on well with 2 out of approx 17

The thing they would most change about school was having shorter hours. But there were other suggestions:

I would change the time school starts at to 11:00 am; that way we learn more as we are more awake

My time at school was spent with people with severe disabilities. I wish it had not been the case

I hate not being able to wear what I want to.

Leisure Time

A range of leisure pursuits were mentioned with some young people spending most of their time out of the house, whereas some seemed to stay mostly at home.

I like to go jogging. I also go bowling with my College Mates on Wednesday nights. I am also a venture scout so we would go hill- walking quite a lot. I also love going down to my cub meetings as I am a leader.

Go swimming. Play computer games, watch TV and play the Wii

Play my playstation, watch TV. Listen to music.

Sleep, ps3, friends, pony & young farmers

Often these activities were done in the company of friends but four mentioned they were mostly alone and three in the company of family members.

On my own

With my mum and sometimes my sister

My family and I go to the cinema or to Burger King as a treat

Some expressed a wish for greater freedom to travel and to see their friends.

Move out. I hate living at home. Well, I don't hate it, but I can't wait to move out.

I want to go into town with my friends but mum wont let me.

I want to learn to drive Travel, move out of my parent's house, get a car that functions properly

After school

Although one person was unsure as to what s/he would do after school, nine mentioned a job and three mentioned continuing their education. Some had a well thought out plan.

Maybe take a year out and go to Hungary. Hungary is a beautiful country. Then perhaps university, study something vague, like English. Take up permanent residence outside Northern Ireland. Get a job, obviously.

Become a photographer.

Would prefer a fun job preferably indoors with subjects such as ICT, geography, languages as these are my strongest subjects

I would like to be like my dad, he is an engineer on a boat. Or work with games.

Most young people were unsure about things that might stop them realizing their ambitions or the help might require. However some made insightful comments:

Someone who understands my disability and gets me relevant training and helps me find a job.

Careers Advisors, family, School teachers

Unable to find sympathetic employers willing to employ me and not being able to get the necessary qualifications

Poor exam results and my lack of confidence

My epilepsy and Asperger's

All but one person mentioned at least one job they might be interested in; with a variety of jobs noted.

Office work and retail work

I am interested in a job like a General Assistant is a grocery shop.

Science-related possibly biologist or Scientific doctor

Unsure but something to do with ICT and in a team

Engineer

Hairdresser work in a coffee shop

Artist work. Photographer.

I'd like to be a Game designer

Journalism. Media production. Something like that.

Engineer

Accountant or something with figures

A rock star or something pretty exciting. Not sure right now, but I have a good careers advisor, so I should be able to work it out in the next while.

They recognised that help from parents, school teachers, career advisers and employers would be required.

Happiness

When asked about what makes them happy, most young people mentioned friends and others specific activities they enjoyed doing.

Spending time with my friends. When I have something to look forward to

Hanging out with my friends relaxing

Having fun by going places with friends, playing enjoyable sports with friends

A sunny day playing football

If they felt unhappy, nine mentioned that they would tell their parents; usually mum but only two mentioned friends and one person said no-one, giving this reason:

In my experience, telling people stuff does more harm than good

When asked if doctors and other health workers could assist them, a variety of views were expressed.

Listen to the patients about their problems and give them advice on how not to worry about their problems or help them through their problems.

Give them medications and advice from talking to other people with this experience.

Be there when I need them, I have had to wait too long in the past.

Finally the young people were asked what they would wish for if given three wishes. They elicited a range of typical teenage responses from having a desk-top computer or really comfortable socks to world peace, end to global poverty and no more killing of animals. Some looked to a future with financial stability, good jobs, plenty of money, health and happiness. However others wrote more poignantly about how ASD affected their lives.

A way to make me stop worrying too much.

To be 4 years old again and have a second chance at life

To be more confident and more social so I will have a great future

I wish I could talk to girls

Just to be happy, really. And never be bored! that is my worst fear - being bored, or worse, being boring.

Conclusions

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.

Section 4: The views of professionals

A self-completion questionnaire with an explanatory letter was distributed to education and HSC staff selected by members of the Operations. The aim was to obtain the reactions of a range of personnel who had a direct involvement with this client group. The topics covered were transition planning, after school services and health and social services.

An estimated 60 questionnaires were circulated and 16 (27%) were returned. These came from The Operations group for the project undertook to circulate a self-completion questionnaire to a range of personnel from the ELBs and two HSC Trusts who had an involvement in young people with ASD. These were: from educational psychologists, specialist teachers, classroom assistant, a school vice-principal, transitions coordinator, speech and language therapists, SENCOs, clinical psychologists and a consultant child and adolescent psychiatrist. Thirteen of the respondents (81%) had more than 5 years experience working with persons who have ASD.

In the past two years most of the young people with ASD known to them had moved on to further education and university after leaving school with only a few mentions of school-leavers going directly into employment, for example in the family business. However one respondent noted:

> *Some young people go into courses that don't suit them and as result then drop out*

A transition co-ordinator also admitted:

> *We are not aware of what all pupils with ASD move onto. We only are aware of (what happens to) a very small number as their plan and outcome doesn't always match.*

The Figure summarises the range of personnel that respondents had some involvement with around transition planning for the young people known to them. This gives some indication of the variety of personnel and services involved.
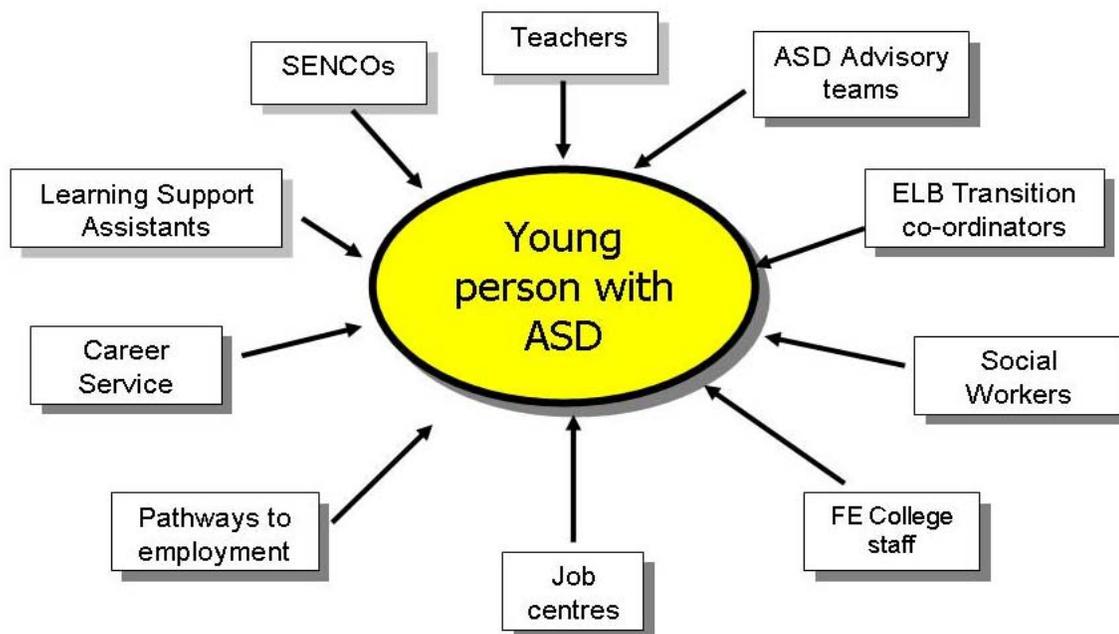
Figure: Personnel and services involved with young people in transition

Transition planning

The most commonly mentioned supports that were required to help young people during the transition from school were:

- Career advice
- A co-ordinated person-centred plan worked out with the young person and his/her family.
- Named professional/co-ordinator/key-worker who works with the young person two years prior to leaving school and in the post-school period.
- Information about available options, courses and opportunities with advice from personnel within FE Colleges
- Structured support at further education colleges or employment placements
- Travel training
- Assistance with work experience or part time employment
- Support for social opportunities and maintaining social networks
- Access to ASD sensitive mental health services if required

Respondents also alluded to the emotional supports required by the young people and their families.

> *Support for anxiety and stress experienced by pupil at time of transition*

> *Carers are usually rather worried about the transition and need lots of reassurance and encouragement*

> *The young people need help developing independence and reducing anxiety levels*

Respondents were asked which of these supports were working well at present. Many found that most were lacking but career advice seemed to be available in certain areas and pupils in SLD schools seem to fare better than those in mainstream school which they attributed to closer contact between HSC staff and these schools.

> *Levels of support vary from school to school. Many schools have good career programmes that begin as early as Yr10 and connect pupils with colleges, work possibilities and training programmes as well as with career officers etc*

> *Classroom Assistant support works well. They accompany pupils to careers conventions, college-help them to make applications for courses and accompany pupils to the world of work.*

However more mention was made about supports that were lacking.

> *Support for student once they have started college courses*

> *Great difficulty accessing mental health services for pupils who do not attend special schools*

> *More joined up approach from services.*

> *No input or links from Health Trust at transition meetings*

> *The training of SENCO's is very ad hoc*

> *Little support to gain and maintain employment*

Various suggestions were made for improved services.

> *Linking up all the information that is available*

Training for careers officers that is specific to pupils with ASD

Better links between FE Colleges and post-primary schools

Further education providers need support and guidance themselves on how to give support and guidance to young people with ASD

Special trained advisor in Colleges to help student on regular occasions throughout their course;

Buddy type helper available in Colleges and work settings.

A better link between Health Trusts and Transition Service within the ELBs

Social groups/clubs etc for ASD or special needs

An overall strategy is needed for transitions

Supports required in further education

Respondents noted a range of supports they felt were needed in further education colleges and universities.

- Tutors trained in dealing with ASD
- A specific ASD support network in place for staff
- Classroom assistant hours
- A link with previous schools and supports they had in place there
- Structured introduction to college
- Help with self-organisation
- A "Home Room" as provided in school to give ASD students a place to relax
- Communication/visual supports to enable ASD to function

Supports required for employment

Likewise a range of supports were proposed to assist employment.

- Employers who have an understanding of ASD
- Support for young people in practicalities of employment e.g. transport, time keeping, money management
- A mentor/ key worker/ designated person within the work environment to ensure the young person understands their tasks/work responsibilities
- Someone (other than parents) that the employer can consult should problems emerge
- Thos who work alongside the young person may need to be aware of their problems (particularly social problems)
- Preparing communication passports and using personal diaries/notebook-rules for social interaction in specific situations
- Links between schools and employers.

Supports for social networks

Respondents made various proposals to help young people develop and maintain friendships and to broaden their social networks.

- Access to social skills training groups to allow them to develop basic social skills;
- Training in ASD to be provided for local youth group leaders (voluntary groups);
- List of local voluntary youth groups/activities who are ASD friendly
- Possibly start up clubs/societies based around their special interests, such as computer gaming.
- A youth forum of ASD youths to discuss/address common issues
- Organised social groups that would arrange meals out or cinema visits etc
- Befriending schemes

Other health and social care supports

Various other support services were noted from which certain young people would benefit.

- Support in helping the young people towards independent living
- Relationship/sex education (already commenced in secondary school but would need to be followed up post secondary education)
- Life skills tuition would be beneficial
- Counselling should be readily available
- Specialised psychological and emotional support;
- Easier access to Mental Health Services
- Parents need support so they can provide help for their child

However respondents also listed various ways in which health and social care services could be improved.

The emphasis on diagnosis is understandable but the only function of diagnosis is to ensure necessary services which should include therapeutic services.

Packages of support, tailor made to individual-not time limited

Back up for parents and carers (as well as the individuals themselves) who have high anxiety levels

Specific staff training to develop skills and knowledge;

Diagnostic services and better intervention/support services;

Key workers to coordinate Person Centred Plans

Increase support to access employment and housing

Have a dedicated ASD department to target this growing group for assistance in direct or indirect services

There is a real dysfunction between autism services and mental health services.

But as one respondent noted their role should be circumscribed:

HSC should provide specialist diagnostic and post-diagnostic services that focus on emotional and psychological well-being for the adult and their parents/carers/partners/spouse. Clearly there is a significant role for other agencies, from Education and Library Boards to the Dept of Employment and Learning.

Conclusions

- 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 if 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 noted in Health and Social Care provision but mostly in topics to be addressed and in style of working. Access to counseling and to mental health services was poor.

Section 5: Conclusions and Recommendations

The section summarises the implications of the findings from this research project and identifies a number of recommendations for improving services to these young people and their families. These were developed through dialogue with members of the Steering and Operations Groups for the Project all of whom had direct experience of working with this group. In addition, a Round Table was held with 22 persons drawn from major stake-holder groups in statutory and non-statutory services to validate the conclusions and refine the recommendations prior to the final report being submitted to the Boards and Trusts.

The recommendations are grouped into five themes that resonated from the various data gathered as well as those found in the international literature (see Appendix 1).

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. In particular:

- Some schools were reluctant to make the adjustments (sometimes small in nature) required by pupils with ASD. Greater awareness of ASD among all school staff would be helpful and the resources to do this are often available but not availed of.

- Likewise some schools are less ready to accept pupils with special needs. This needs to be addressed within the implementation of the Department of Education policy.

- Transition co-ordinators are not allocated to non-statemented pupils. However these pupils need to have some access to information and advice within and beyond school. This will become a bigger issue if fewer pupils are given formal statements of special educational needs in the future.

- Information on post-school placements of pupils needs to be collated and analysed. In some Boards this is starting to happen. This is a useful means of identifying and tracking pathways that other pupils could follow.

- Pupils with ASD could be at risk of suspensions, expulsions and refusals to attend school. This information could be tracked within the ASD database maintained by the Boards. Alternative placements may need to be sought so that their education is not disrupted.

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. Indeed plans are in hand to extend this expenditure by both Departments. Thus far in Education, these monies have been directed mostly at children under five and in primary education, although this is extending into post-primary provision. Likewise DHSSPS has announced an Autism Action Plan for improved health and social services. 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. 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 been identified as having ASD.

Further Education

Based on the successful experience in mainstream schools, improved provision over the next three to five years could include:

- The provision of more learning support assistants in Colleges of Further Education to assist individual students.

- The development of staff posts within Colleges that are equivalent to SENCOs who provide one point of contact for students, families and support staff as well as being an advocate for students within College.

- An expansion of the counselling and advisory services within Colleges particularly for students who may experience personal and emotional problems.

- The provision of a physical space to which students with ASD can withdraw and in which extra tuition could be provided to smaller groups and/or individuals.

Comparable improvements may need to be made by Universities although to a lesser extent.

Careers advice and vocational training

Given the rising numbers of school-leavers with ASD, the Department of Employment and Learning should also consider:

- Further development of the Careers Service and the Pathways to Employment Service to offer guidance and support to young people with ASD and their families during their school years and after school.

- An expansion of vocational training and supported employment services designed to meet the particular needs of young people with more marked ASDs. These may need to be delivered through specialist agencies such as Orchardville Society and NOW in the Belfast area who have the requisite experience in this area. This could be done through contracts with DEL. However there is a dearth of similar agencies elsewhere in Northern Ireland.

Professional Development

The above strategies need to be complemented by ones that equip existing services to better respond to the particular needs of young people with ASD. This would include:

- Training for teaching staff in FE and Universities on adapting their teaching approaches to suit the young people. A similar strategy has proved successful in primary education and is being rolled out in secondary schools using staff from Education and Library Boards and Health & Social Care Trusts. Their work could be extended into third level education.

- Similar training being available for staff in the Careers and Disablement Advisory Services.

- Education initiatives aimed at employers and co-workers on the contribution that people with ASD can make to the workforce through work experience placements, training placements and as paid workers.

A proactive policy that increases further education and employment opportunities could avoid young people with ASD joining the long-term employed with the associated costs that this

brings. This point is especially applicable to young people from more deprived backgrounds who have increased chances of becoming involved with the criminal justice system.

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.

Possible strategies in this sector would include:

- Training and awareness raising about ASD among leaders and staff of community organisations with resource materials provided that they can share with their colleagues.

- The development of a buddy/mentoring schemes within larger sports and youth groups as a means of integrating young people with ASD.

- Involvement of the young people in voluntary work in local communities.

- Provision of social skills training but in contexts and using approaches that appeal to young people with ASD. This might be done within health and social care settings or in mainstream youth settings rather than within schools to prevent young people being singled out from their peers.

- The development of Drop-In Centres where young people with ASD could meet one another, obtain information and advice, and promote their advocacy and community engagement. Similar strategies have been proposed for persons with learning disabilities and mental health problems.

- The provision of information by District Councils and organisations such as NICVA about options available in local communities and neighbourhoods.

- Access to counseling and advice services that are ASD-friendly and aimed at teenagers and young adults.

Some investment may be required from Education and HSC to fund the start-up costs of these initiatives. But again this may prevent the costs entailed in providing specialist supports if the young people with ASD develop mental health problems or they break the law.

The above service developments might also address the needs of siblings of young people with ASD.

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. Areas that require attention are:

- During the transition process (from 14 years onwards) families are given the name of one person within a defined locality who can sign-post them to services and supports across a range of agencies – Education, HSC, DEL as well as the voluntary and community sector. Transition officers are an example of such a role although their work is limited to teenagers

with a Statement of Special Educational Needs. The role needs to extend through the series of post-school transitions that young people encounter up to 21 or 25 years of age.

- Information leaflets and web-sites are developed that describe the available supports and explain the eligibility criteria for accessing particular services. A single point of contact could be provided either regionally or in each Trust area (e.g. by a voluntary organisation).

- Opportunities are provided to families of teenagers with ASD to attend training courses on pertinent topics to them that give practical advice and guidance, as well the opportunity to meet other parents. This could be done by Health and Social Care staff in conjunction with education colleagues but voluntary organisations might be better placed to deliver such courses at times that are better suited to parents.

- The work of the newly appointed Family Support workers in various HSC trusts should extend into the teenage years, with one of more of these workers perhaps specializing in support for parents of teenagers and young adults.

- Parents should be offered an assessment of their needs as carers in recognition of the pressures that ASD can place on them and other family members. Direct payments could be offered as a means for them to obtain 'respite' breaks.

5. Health and Social Care Services

Health services

There is limited evidence from this study that any major investment will be required by Health and Social Care Trusts 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. Indeed most of the increased number of young people identified as having ASD seem to be leading broadly 'normal' lives and their aspirations is for this to continue. Hence to 'medicalise' their condition may be a major dis-service to them (see Appendix 1).

In this respect the label of 'ASD' that they have been given is largely for use within the education system. Indeed a similar phenomenon exists for children identified as having mild/moderate learning difficulties; only a minority of whom have ongoing support needs once they leave school.

Nonetheless improvements to certain Health and Social Care services may be beneficial to young people with ASD but also to other children 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 family as well as to teachers and pastoral care staff within schools.

Also non-statutory agencies organisations already involved with young people 'in need' – for example, Contact Youth, NSPCC – could be supported to respond to the needs of young people with ASD.

Possible strategies could include:

- Training in ASD for primary care staff and those working in non-statutory organisations on adapting their supports to the needs of the young people and their families.

- Greater emphasis on mental health promotion among young people across a range of community services and settings.

- The provision of workshops to young people on specific topics such as anger management, self-harm and eating disorders.

- Access to Cognitive Behaviour Therapy and other 'talk therapies'.

- Greater clarity is needed about referrals from education to CAMHs and access to emergency assessments for young people at risk of self-harm.

- Increased ASD expertise is needed among existing CAMH and Child & Family teams so that they are better placed to support primary care staff and to deal with the possibly small number of referrals who may require more specialist assistance.

However priority should be given to the first four areas listed as their focus is on early intervention and prevention. Arguably though, this culture shift would be one of the biggest challenges to current service systems.

A small proportion of young people will require more specialist help but it seems that existing provision for teenagers with mental health problems is over-stretched at present. Proposals for improvements should be cognizant of the needs of young people with ASD.

Social Services

For adult persons with ASD, their legal entitlement to social services is not clearly defined. However the forms of service from which they (and indeed other persons with developmental disabilities) might benefit include:

- Individualised payments to purchase support packages: these could assist with accessing education and training, social activities and personal development.

- The provision of training courses in Life Skills, such as independent travel, sexuality and relationships.

- Access to information and advice throughout the life span. This might take the form of an extension to the Family Support service evolving for children.

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.

These arrangements might grow out of the Executive's Action Plan in response to Bamford Review, and/or the Regional ASD Network set up by DHSSPS. However clear leadership and commitment is needed to make this happen. Indeed this approach would be beneficial with other client groups such as learning disability, mental health and brain injury.

If an integrated arrangement cannot be achieved at a Departmental level, then local schemes possibly evolving out of existing partnerships between HSC Trusts and former ELBs should be encouraged and their progress monitored so that new styles of working are documented and evaluated which in due course could be implemented regionally.

Further Research

This project has identified a number of areas in which further research would be helpful.

- We need more information on children with ASD living in the so-called 'hard-to-reach' or 'dysfunctional' families. They may have particular support needs that this study has not captured.

- The needs of 'looked after children' with ASD have not been considered in this study. Other vulnerable populations are teenagers who have dropped out of schools or those who have offended.

- The views of a wider range of young people with ASD would provide a more comprehensive account of their aspirations and support needs.

- A longitudinal study of young people during their post-school years would provide valuable learning about what assisted and hindered their career development.

Concluding comments

Arguably one over-riding conclusion emerges from the experiences, concerns, and aspirations recounted by the participants in this study, is that young people who are classed as having ASD deserve the same life chances as their peers.   Often this can happen through adjustments to the way mainstream services are organised and delivered which ultimately will benefit many others with special needs. Although increased resources may be required to achieve these adjustments, the bigger challenge is changing the cultures and practices that pervade our service systems.   This needs to be done from the 'bottom-up' as well as from the 'top-down'. The strategy of adapting services for one person at a time has proven very effective in creating supports for other persons with disabilities and should be just as effective for young people with ASD.

One teenager in this study had this wish for the future.

> *To understand myself better and for other people to understand me better.*

It's as simple and as difficult as that!

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Appendix 1: Review of Legislation and Literature

Throughout the UK, rising numbers of children are being assessed as having an Autism Spectrum Disorder (ASD) with rates in excess of 1 per 100 now reported among 9-10 year olds (Baird et al., 2006). These children invariably experience difficulties in communication and social interactions which make it harder for them to interact with their peers and increase the likelihood of their social exclusion in future years. Special efforts are need to promote their inclusion in society.

This review begins by outlining the social consequences of disability that provides the rationale for recent legislation such as Disability Discrimination Acts. Issues and research relating to social exclusion and people with ASD, their further education and employment are then reviewed.

Rethinking disability

In recent years, physical disability and to some extent, intellectual disability has been re-conceptualised more as a social rather than a personal issue. This thinking has not been applied to ASD. Indeed much professional practice and service delivery assumes that the disability is a characteristic of the person and hence people can be categorised into those who are '*disabled*' (or '*autistic*' or '*on the spectrum*') and those who are not. This has been labelled the 'medical model' of disability because of its emphasis on finding a cause (usually in the person's biology) and trying to effect a 'cure' either through chemical interventions (including diets) or behavioural treatments.

In this model of disability the focus is on defining and categorising a person's impairments or limitations in functioning with little or no attention paid to the social, cultural and physical environments in which people live and which can constrain their lifestyle and levels of functioning. Hence when children attend at a clinic the doctor will conduct medical examinations and the therapists may use tests to assess their communication or sensory impairments. They may show little interest in wider family circumstances and although they may make recommendations relating to the child, they will probably not feel able to help with other issues that may have a greater impact on the family such as poor housing, mother's depression and unemployed father.

ASD – a social disability?

Disabled activists – including those with ASD - have been to the fore in criticising this medicalised view of disability.

- They argue that most definitions of a disability stem from a medical emphasis and do not reflect issues of importance to people with disabilities, such as lack of access to education, employment and housing.

- Terminology is used that is devaluing and stigmatising of persons with disabilities, and which can easily be used to justify low expectations and denial of opportunities. Expressions like "*They're autistic*" can sound very dismissive.

- The focus is on people's deficits with little attention to their talents and competences or how these strengths can be used to overcome or compensate their weaknesses.

An alternative way of thinking about any disability has been termed the 'social model of disability'. Promoted initially by disabled people themselves, this model views disability as the outcome of the interaction between a person with an impairment (be it biological or cognitive)

and the environmental and attitudinal barriers he/she may face. In short, people are disabled by the society in which they live.

In the social model, the key assessment is in terms of the type and extent of the accommodations or interventions required to the environments so that the person functions as well as other people in their society. Obvious examples are the provision of lifts instead of stairs and access to hearing aids. Both of these accommodations will reduce the disabilities experienced by either wheelchair users or hearing impaired persons. For people with ASD, the adaptations that will most help them may be more in people's behaviours and expectations.

In this way of thinking about disabilities, the focus of interest in both assessment and treatment is placed on the **barriers** that prevent people with disabilities to participate fully in society and the supports and adaptations that would enable this to happen. Disabled activists have focussed especially on access to education, employment, community facilities, transport and housing as these are primary determinants of social inclusion in most societies.

This model of disability better reflects the emphasis in Government policy on social inclusion; encapsulated in slogans such as 'full participation' and 'equality of opportunity'.

International Classification of Functioning

But perhaps there is an element of truth in both views of disability. We need to identify and understand any differences in the biology of the person as well as appreciating the impact that social influences may impact on how these differences are manifest in the person's life.

The World Health Organisation in their International Classification of Functioning, Disability and Health (abbreviated to ICF) (2001) takes this approach. This framework aims to encompass all aspects of human health and health-relevant components of well-being. It is applicable to all people, not just those with disabilities.

A person's functioning is conceived as a dynamic interaction between health conditions and contextual factors both personal and environmental. ICF does not classify people into discrete groups but rather aims to describe the situation of each person within an array of health-related domains (including bodily impairments and illnesses) and in the context of environmental and personal factors that are known to influence their levels of functioning with society. Each person is given an array of codes – usually between 3 and 18 to describe their particular characteristics.

Further Information is available at: http://www.who.int/classifications/icf/en/

The main lesson however, is that we need to see the growing child or teenager or adult with ASD as a person not apart from society but a person who is striving to become part of society. Hence our assessments and interventions must be geared to the latter at all times.

Legislation

The United Nations draft convention on the Rights of Persons with Disabilities (2007) states in Article 19 that Governments should recognise:

"the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community".

One way in which the UK Government has fulfilled this obligation is through disability discrimination legislation; first introduced in 1995 but with updates since then. In Northern Ireland this is the Disability Discrimination (NI Order) 2006. Developmental disabilities such as ASD are covered by this legislation as well as many other impairments and chronic illnesses.

> **Definition of disability**
> A person with "physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities"
> **Disability Discrimination Act**

This law states that disabled people must be given equal opportunities in terms of access to employment, buildings, and to goods and services. It also requires schools, colleges and universities to provide information for people with disabilities and make suitable accommodation for their needs. There was initial debate about what constituted 'services' but parliamentary challenges have confirmed that services include health and social services. This covers access to GPs and acute hospitals as well as services provided to meet their specific needs. More recent amendments have extended the legislation to social clubs and house rentals.

Further information about the Disability Discrimination Order is available at:

http://www.equalityni.org/sections/default.asp?cms=your%20rights_Disability%20discrimination&cmsid=2_142&id=142&secid=2

Further Education and Training

People with ASD have the same rights as other students to access further education when they meet the entrance requirements in terms of educational qualifications.   There is also a legal requirement placed on colleges and universities through the Special Educational Needs Oder (SENDO, 2005) to ensure that they:

- Make 'reasonable adjustments' to all policies, procedures and practices to ensure that a disabled pupil/student is not placed at a substantial disadvantage compared to non disabled pupils/students.   For colleges and universities, this particular duty also applies to the provision of auxiliary aids and services, and to physical premises.

- To work towards making school life and the education experience more accessible to disabled pupils/students and prospective pupils/students, for example, in terms of premises, the curriculum and information.

Further information about the SENDO (2005) Order is available at:

http://www.equalityni.org/archive/pdf/SENDOBrief10.pdf

Experience is still developing on how colleges will respond to meeting the needs of students with ASD. Many of the developments within primary and secondary education that have assisted the inclusion of pupils with ASD could be applicable in this sector (Jordan and Jones, 1999). These include:

- The provision of ASD training to all school staff.

- Access to learning support assistants in classrooms.

- Having a designated staff member in the school (SENCO) to co-ordinate special needs.

- Advice from specialist teachers and educational psychologists.

- Individual educational plans and regular reviews.
- Provision of social skills training for pupils.

Adreon & Durocher (2007) in their review of transition from school to college identified the type of difficulties students may encounter across various domains, including socialization, communication, independent daily living skills, academic functioning, and self-advocacy. They describe the supports students with high-functioning ASD need to succeed in meeting the organizational, academic, and social demands of college life.

Hillier et al (2007) reported promising results from an eight week social and vocational skills support group for adolescents and young adults with ASD. "Participants reported that they made friends with others in the group and maintained contact by telephone and e-mail. They also organized and initiated gatherings, such as attending one group member's high school play, watching the Super Bowl together, going bowling, and so on. The members noted changes in their behavior and an increased effort on their part to interact with other persons socially. They reported more positive attitudes toward gaining employment".

Perspectives on social exclusion

People with ASD and their families are those most affected by the reality of social exclusion. Here we report their views on social exclusion – see if they echo what you noted or discussed.

When researchers (Muller et al, 2008) have talked with groups of people who have ASD, they recount a number of common experiences:

- *a profound sense of isolation* – people spoke of having 'acquaintances' but no real friends.

- *difficulty initiating social interactions* -   they found that trying to initiate conversations with others made them anxious and stressed*.*

- *challenges relating to communication* - People with ASD seem to have to learn many of the skills - social and otherwise - that people without ASD learn easily through observation and imitation. One person put it this way: '*I can't pick up on body language or hidden meanings, or what people are really saying, when they're saying that in-between-the-lines stuff.*'

- *longing for greater intimacy but fearful at the same time* – the desire for closer relationships was tempered though with some reservations, as one man said: '*I'm looking for a little bit more . . . closeness and friendship without getting too close, because I myself have a very limited tolerance of closeness in relationships*'.

- *desire to contribute to one's community* – through volunteering and helping others with ASD. They had talents they wanted to share.

- *They needed to keep developing greater social/self-awareness* – people were striving to develop their social skills through reading about ASD, meeting with others who have ASD and so on. As one person put it: *I know that a lot of times when I talk, I bore people, because I talk too much, and go into too much detail. So I've been working to try and make things more brief.*

Parental experiences

Parents of children and young people with ASD also experience social exclusion ; for themselves as well as for their son or daughters. A survey undertaken in Britain by the National Autistic Society (Barnard et al, 2000) found that three out of five parents of young adults with ASD believed their sons or daughters were socially excluded. Half the parents said that their son or daughter has not been able to meet people and make friends outside their home as much as they would like, and only 11% have access to paid employment.

Parents wanted to see their adult children progress in relationships, socialising, educational opportunities and work. The things they felt would help them to become more included were:

* A more understanding and respectful public/better public awareness (34%)

* Improved social skills/better and more stimulating social activities and opportunities (20%)

* Suitable employment (10%)

* More friendships and/or relationships (8%)

Research studies

Howlin (2000) and Tsatsanis (2003) reviewed the literature on outcome for adults with high-functioning autism or Asperger syndrome and found that only a minority had received college or university education, lived semi/independently, had close, spontaneous friendships, were married, or had a paid job. The social and communicative impairments of adults with ASD often give rise to lower levels of social functioning than would be expected on the basis of their linguistic and cognitive abilities. However Renty & Roeyers (2006) found that the support people received was a better predictor of a person's quality of life rather than their lack of skills.

In the main, support is provided to adult persons by families as there is a dearth of suitable community-based services (Saldana et al., 2009).

Plimley (2007) provides a useful review on measuring quality of life in persons with ASD

The consequences of exclusion

More generally, research with marginalized groups has identified certain concomitants of exclusion, including:

* *Decreased quality of life.* If the person misses out on opportunities for further education and employment then their earnings potential is reduced. Hence they may have a poorer standard of living and be unable to participate in leisure pursuits.   Poverty is not a happy place to be!

* *A lack of friends and close personal relationships*. People see relationships as the key to a 'good life' . They are also protection against abuse and exploitation.

* *Increased risk of experiencing mental health problems* - such as depression, anxiety and more serious mental illnesses. Social exclusion can sap a person's self-confidence and self-esteem. Teenagers and adults with Asperger's Syndrome are more prone to experience mental health problems (Sterling et al, 2008).

Inclusion in employment

In the National Autistic Society survey of over 1,000 families who had a son or daughter with ASD (Barnard et al, 2000), it was found that most adults with Autism or Asperger Syndrome have aspirations to be in a paid job but few actually manage to achieve that goal at present.

> *There are a few things I would like to follow through within the next ten years. First of all, and most importantly, my work. Secondly, friendship: I would like to obtain a variety of different friends... I think later on I would like a relationship. That relationship will only be a meaningful relationship with the right person... that is the third, I guess least important, thing of the three.'*
> **A young woman with Asperger syndrome.**

One mother commented:

> *'Even a few hours of work, either paid or unpaid. He doesn't mind not earning the money but needs more structure to his day and more purpose in his life to be fulfilled. He has a qualification in advanced computer studies but at present is unable to get a job. He needs someone with him such as a job coach for support.'* **Parent of very high functioning adult living in rented accommodation with some support.**

But when people do get a job, there can be difficulties in keeping it. Here's one man's experience of employment.

> *People with autism have bad experiences with jobs. It is not that we do not work hard, or have problems with being prompt, not being on time, or unwilling, because we are not that at all. It is that we are not very good at dealing with people in social situations. More jobs get lost because of not being able to work together than any other cause. It can range from just being odd, to taking some time to learn things, like I deal with, to having temper tantrums and behavior problems. The most important rule at work is to get along with others at work. I think that jobs usually are 80% social (conversation, lunch, breaks, chit-chat) and 20% work. People with autism are better the other way around!*
> **Joe – cited in views of people with ASD**

Our knowledge of the life-style of adult persons with ASD is rather sparse as to date most research has focused on children. However one common finding is the small numbers of people with ASD in paid work. In England, researchers reported on 68 individuals who met the criteria for autism (Howlin et al, 2004). They were first seen at 7 years of age (range 3–15 years) and at follow-up their average age was 29 years (range 21–48 years).

- Eight (12%) were working independently and one man was a self-employed fabric printer, although this did not provide him with a living wage. Most of the jobs were low level and several had been found via parental contacts, rather than through the open job market; pay was generally poor.

- Fourteen individuals (21%) worked on a supported/sheltered or voluntary basis (2 worked for the family business and one in a shop run by his residential centre).

- Five other individuals carried out some routine work (weaving, gardening, bakery, etc.) within the residential centre.

- Ten further individuals were involved in off-site schemes organised by their day or residential centres.

- The remaining 27 were described as being in general work/leisure programmes within their day or residential units.

Most remained very dependent on their families or other support services. Few lived alone or had close friends. Communication generally was impaired, and reading and spelling abilities were poor. Stereotyped behaviours or interests frequently persisted into adulthood. Ten individuals had developed epilepsy.

Overall, only 12% were rated as having a 'Very Good' outcome; 10% were rated as 'Good' and 19% as 'Fair'.   The majority was rated as having a 'Poor' (46%) or 'Very Poor' (12%) outcome.   Individuals with a childhood performance IQ of at least 70 had a significantly better outcome than those with an IQ below this. However, within the normal IQ range, outcome was very variable and, on an individual level, neither verbal nor performance IQ proved to be consistent prognostic indicators.   The authors concluded: "although outcome for adults with autism has improved over recent years, many remain highly dependent on others for support" (p. 212).

What needs to happen?

Three strategies have been suggested to get more people with ASD into employment.

- Further and Higher education institutions should be encouraged to recognise the social needs of students with autism and Asperger syndrome who may form part of their student populations. The same strategies reviewed in the previous session can apply here.

- Also work should be undertaken with employers to achieve a better understanding of the needs of people at the more able end of the autistic spectrum and push for more 'reasonable adjustments' to be made in the workplace so that people with autism and Asperger syndrome can be employed.

- People with ASD need to be supported into employment, for example they should be trained on the job and have the support of a 'job coach'.

Supported employment

Supported employment is based on the principle of 'place, train and maintain'. Job opportunities are found for the person in line with their talents and interests. He or she is then trained on-the-job by a 'job coach' who also adjusts the working environment if necessary and enlists the assistance of co-workers.   The job coach gradually fades out but remains in contact with employers should any problems arise.

This approach is directly counter to the 'readiness model' which aims to prepare people for work through special training programmes; a model that had dominated in the field of disability nationally and internationally. However a low proportion of trainees actually obtained paid employment in the open labour market from this form of provision.

Does Supported Employment Work?

The outcomes of a 2-year supported employment project were evaluated for high functioning adults with ASD in the London area (Mawhood and Howlin, 1999) . Thirty individuals were contrasted with a control group of 20 persons with similar characteristics. Thirteen different employers (mostly multi-national companies) were involved and several were willing to take more than one employee because of their positive experience of employing someone with autism. Over the course of the project significantly more of the supported group found work than did the controls; job levels were higher; they were in work for a greater percentage of time and they received significantly higher wages.

Although the costs of the specialised inputs were high initially they reduced over time. The authors concluded: "*One of the most expensive and time-consuming aspects of the scheme but one that appeared to be crucial for success, was the need for close liaison with employers in order to explore appropriate job opportunities and to match these carefully to the skills and abilities of individual clients … Although some elements of the scheme can continue to be supported through government funding, no financial provision is available for this initial and essential stage of job findings*" (p. 229).

Keel, Mesibov and Woods (1997) also reported good results from a supported employment program provided by Division TEACHH in North Carolina. They used three models: supported employment, dispersed enclave model and mobile crew model. Within each there was an emphasis on utilizing individual strengths and interests, identifying appropriate and providing extensive long-term support, They claim a retention rate in employment of 89% although it is not clear how much of this was in competitive employment.

Similarly a supported employment project for 15 persons based around applied behaviour analysis (McClannahan, Macduff and Krantz, 2002) reported 11 persons were in employment while 4 received in-house services because of low-rate but severe aggression, intermittent but severe self-injury, or serious health problems.   The work experience of these adults with autism is quite diverse and includes kitchen utility work, grounds maintenance, hotel housekeeping, data entry, factory product assembly, laundry work, filing, and collating, and merchandise receiving. The authors also noted that some parents and guardians preferred part-time employment because of concerns about job stress, loss of Social Security benefits, and loss of funding for adult services.

A Scottish study placed 30 persons with 'complex needs' (including Asperger Syndrome but mostly other groups) in employment using a supported employment model (Weston, 2002a). However most worked one day a week for between one and four hours, a quarter worked two days a week (for three to five hours a day), and a few between three and five days a week (for three to four hours a day).

They recommended that there be "consistent, long-term funding for supported employment agencies, so they can effectively support people with complex needs into, and in, work. Funding could be linked to soft indicators (e.g. individuals' feedback on choosing, getting and keeping a job) as well as realistic targets to move people into work" (p.4).

However Weston's (2002b) review of supported employment and people with complex needs identified a number of barriers to success within the British system: the benefits system, a lack of long-term funding, aspects of employment policy and geographical variation in provision.

Cimera and Cowan (2009) conducted a large-scale US survey and found that individuals with ASD were employed at higher rates than other disability groups but that they tended to work fewer hours and earn less in wages per week. Jarbribnk et al., (2007), in examining the costs of supported employment services in Sweden, noted that they were high but that a lack of such services would have negative resource consequences for the economy in the longer term. Likewise Lawer et al (2009) in the United States found higher costs for supporting people with ASD but that the employability was highly associated with on-the-job supports. Nonetheless as a group they were more likely than other disability groups to be refused services as they were considered to be too disabled.

Gerhardt (2007) argued that greater emphasis needed to be placed on employment during transitions from school and proposed five principles to guide this: (1) considering all learners

to be "employment ready"; (2) viewing first jobs as learning experiences; (3) promoting creativity in job development; (4) providing co-worker training; and (5) developing active ties with the local business community.

Conclusions

- It is possible for people with ASD to take part in some form of employment.

- Many will require some extra assistance and support to make this possible. The model of supported employment allied with access to further education and training are the two most promising strategies.

- Services and supports are not widely available to school-leavers and to their families.

- Being long-term unemployed increases the risk of young people becoming depressed and losing confidence in themselves.

Implications for transitions

Hendricks and Wehman (2008) in their review of studies into transition from school to adult life made the following recommendations that brings together many of the issues raised thus far.

- "Planning for transition needs to begin when students are between 10 and 13 years old, with more serious planning occurring as the child enters the early to middle teen years.

- Efforts are needed to improve the transition planning process for adolescents with ASD. Placing the individual at the center of the transition process is a pivotal component of planning that has been greatly overlooked.

- Student goals should include the full range of community pursuits and should not be based on perceived student limitations.

- Adolescents require instruction in skills related to community, employment, home, and leisure as well as academics.

- Strategies for remedying communication, socialization, and behavioral deficits that profoundly and perpetually affect the individual are critical.

- Learning opportunities need to be provided in a variety of settings, including the special education classroom, the general education classroom, out-of-classroom school environments, and community settings.

- Meaningful integrated employment should be a goal for all individuals with ASD who wish to work and should be the first choice offered.

- For adolescents leaving school, learning specific work related skills is necessary. Such skills should focus on not only job-related tasks but also, more important, the interpersonal skills that will foster a positive work experience.

- The development of strategies specifically designed to increase community participation is essential to ensuring equal opportunities for this group".

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Appendix 2: Membership of Groups

Steering Group

Aidan Murray, Health and Social Care Board (Chair)

Martin Clarke, Belfast Education and Library Board.

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

John Veitch, Belfast Health and Social Care Trust

Operations Group

Roy McConkey, University of Ulster/Health and Social Care Board (Chair)

Petra Corr, Belfast Health and Social Care Trust

Deirdre McHugh, South-Eastern Education and Library Board.

Catherine O'Flaherty, Belfast Education and Library Board,

Marisa Smyth, South-Eastern Health and Social Care Trust

Anna Shephard, South-Eastern Health and Social Care Trust