autism education trust

Outcomes

Educational provision and outcomes for people on the autism spectrum

Full technical report

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List of abbreviations

Abbreviation	Stands for
AET	Autism Education Trust
ARB	Autism Resource Base
ASD	Autism Spectrum Disorder
CASPA	Comparison and Analysis of Special Pupil Attainment
DCSF	Department for Children, Schools and Families
DfE	Department for Education
DoH	Department of Health
EYFS	Early Years Foundation Stage
FE	Further Education
LA	Local Authority
LSA	Learning Support Assistant
NAS	National Autistic Society
NHS	National Health Service
Ofsted	Office for standards in education
SALT/SaLT	Speech and Language Therapist
SEN	Special Educational Needs
SEND	Special Educational Needs and Disability
SENCo	Special Educational Needs Coordinator
TA	Teaching Assistant

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1. Introduction to the Autism Education Trust and the research

1.1 The Autism Education Trust

The Autism Education Trust (AET) was launched in November 2007 with funding from the then Department for Children, Schools and Families (now Department for Education. The AET is dedicated to coordinating and improving education support for all children with autism[1] in England.)

The AET aims to create a platform for voluntary, independent and statutory providers to plan and develop appropriate autism education provision across all education settings, including early years.

There is an Expert Reference Group that provides a breadth of experience to inform the work of the AET, to feedback to government departments, and to be a representative of groups of stakeholders in autism education. A Programme Board ensures that the work of the AET reflects the strategy agreed in consultation with the Expert Reference Group and other stakeholders. The AET has a Youth Council to capture and share the views of young people on the autism spectrum and their siblings.

The AET plays a vital role in highlighting the importance of educating children and young people with autism using evidence-based services and practice. Through its reports and communications, the AET disseminates to the public about key issues in the field of autism and education. The AET also has a key role in communicating the information from its reports to those individuals who make local or national policy decisions about education for children and young people on the autism spectrum.

www.autismeducationtrust.org.uk

[1] Throughout this report we refer to people "with autism" or people "on the autism spectrum" to include all those individuals who have a diagnosis of autism, Asperger syndrome and Pervasive Developmental Disorder not otherwise specified.

1.2 Research aims and questions

The AET believes that all children and young people with autism should receive an education which enables them to reach their individual potential to engage in society as active citizens. Individuals, families and professionals should be informed, supported and equipped to enable this to be achieved.

In late 2010, the AET announced a call for proposals to explore how current educational provision in England is preparing children and young people with autism for good adult outcomes.

The central questions asked were:

1. **What do stakeholders regard as "good outcomes" for adults from across the autism spectrum?**
2. **Are current policies and practices for educating children and young people with autism designed with planning for good adult outcomes in mind?**
3. **What assessment measures are currently being used in schools and are they measuring the right things to help children and young people reach a good outcome?**

In answering these questions, data were to be gathered on current educational practice and on whether educational planning was being made to meet desired adult outcomes. Good practice and areas for improvement were to be identified.

These data were collected via a **literature review**, a **survey** with key stakeholder groups, **focus group discussions** and **individual interviews**.

Of importance to this research was to gather information from across the age and ability range of individuals on the autism spectrum, and from a sample of educational settings.

1.2.1 Defining good adult outcomes

A central tenet of education is to provide children and young people with the skills to fully contribute to society. For many people, a good outcome will be a job, having a partner, being part of a social network, having a home, going on holiday, enjoying hobbies and feeling happy. But clearly what is a good pattern of outcomes for one person might be completely different for another. Indeed, it may be that someone with autism has a very different set of desired outcomes and so we should be mindful not to make assumptions on their behalf based on our own conceptualisation of what constitutes a "good outcome".

Interestingly, there is very little published about what people generally regard as good outcomes for adult life; there is an even greater paucity of literature defining good outcomes for those with special educational needs (SEN). An important starting point in this report, therefore, is to learn about the range of opinions of what good adult outcomes should be for a person on the autism spectrum and how opinions may differ from one stakeholder group to the next. It is only by defining what good adult outcomes should look like that we can begin planning educational provision to achieve those goals.

1.2.2 Educational planning for good adult outcomes

Especially when autism is diagnosed early on in life, educational planning will span across a number of provisions, requiring significant coordination of services. The young person may be transitioning from one school to another or from school on to 6th form/Further or Higher education. Continuity of educational planning across different settings in terms of meeting the young person's longer term outcomes is very important.

In the present research project, we asked stakeholders about the types of educational planning they use in the short and longer terms. Are there particular guidelines for teaching staff to advise them on what outcomes should be aimed for? What restrictions or opportunities are there for educational planning within the current National Curriculum framework? In terms of practitioners' own educational planning, to what extent do they involve the young person with autism or the parent/carer? What are the opinions of children and young people with autism regarding the provision they currently receive at school and where could there be improvements?

These questions were designed to elicit information on the extent to which current curricular and educational practice is focused upon preparing young people with autism for adult life.

1.2.3 Assessment measures and how they relate to adult outcomes

Assessments are used to guide educational planning and to make sure children and young people are gaining the skills and knowledge they need to reach their educational targets. Typical assessments may include: school examinations to relate a child's progress to National Curriculum level descriptors; standardised assessment measures that may be linked to a specific intervention; bespoke measures developed in-house by the school. Schools select from a range of possible assessment tools but little is known about how teaching staff make these selections.

Our focus in the current research was to survey the range and types of assessment measures being used in schools, for young people with autism. Is there any specific guidance as to why one assessment measure was selected over another? How are these assessment data used to inform and guide the future development of curricula towards meeting good adult outcomes? Teachers were also asked about the process of collecting and analysing data, and reporting findings to young people and their families.

1.3 A description of how the report is structured

The main body of this report is organised around the three key research questions outlined previously.

For each of these three main questions there will be:

- **a review of the research and policy literature**
- **a presentation of the survey data that were collected as part of this research**
- **descriptive data presented on the findings from the focus groups and interviews with key stakeholders**
- **a summary of the findings**

In the next section we provide a brief introduction, which is followed by an outline of the research methodology.

2. Background

2.1 Defining the autism spectrum

Individuals on the autism spectrum experience difficulties in social interaction and communication, and have rigid and repetitive ways of thinking and behaving (ICD-10, 1992). These behaviours are thought to be underpinned by difficulties in both the flexible generation of ideas and the understanding of, and thinking about, other people's thoughts and feelings. Lower or heightened sensitivity to sensory information, and interests in particular sensations, are also common. People with autism are at increased risk of developing childhood psychiatric or mental health disorders, especially anxiety and attentional difficulties (Simonoff et al., 2008).

There is, however, much variation in the way that children and young people with autism show these different behaviours. A significant proportion of individuals with autism have an additional learning disability, whereas others will have average or advanced intellectual abilities. Difficulties with understanding and expressing language vary greatly. For some individuals spoken language is limited or absent altogether, while for other individuals speech can be fluent but their use of language to communicate can often lack social intent (e.g., conversational turn-taking). Furthermore, stereotyped and inflexible behaviours range from repetitive movements of the body to restricted special interests (e.g., prime numbers, train timetables, drain pipes) and an insistence on sameness.

The full autism spectrum therefore includes children, young people and adults with very different patterns of behaviour and skills – an observation that first prompted Lorna Wing to coin the term "autism spectrum" to capture this wide variability (Wing and Gould, 1979). Autism is a developmental condition and the presentation in any individual will change with age, with some children experiencing periods of rapid improvement and others stasis or the plateauing of development.

The number of children on the autism spectrum in the UK population is estimated to be one in a hundred (Baird et al., 2006), meaning that *all* schools are likely to include young people who are somewhere on the autism spectrum. The prevalence of autism is 4 times higher in boys than girls, but the reasons for this sex difference have not yet been determined. Autism is a strongly genetic condition although it is now recognised that this consists of both heritable and sporadic (non-inherited) forms. Non-genetic factors may also play a role in causing autism, but such instances probably account for a minority of cases and have yet to be identified. Until recently, many children with autism were not diagnosed until 4 or 5 years of age, and even later for some children with Asperger syndrome or autism with good spoken language skills and of average or above average ability (sometimes referred to as 'high functioning autism'). However, progress has been made in the earlier identification of autism, and many children, especially those with a more classic presentation of autism in combination with language delay, are now first identified in the pre-school period (see Charman & Baird, 2002).

2.2 Current educational provision for children and young people on the autism spectrum[2]

Inclusion within mainstream schools is generally considered to be the ideal for any child, and indeed the majority of children on the autism spectrum in England are educated in mainstream settings (DCSF, 2008). However, as children with autism vary widely in terms of intellectual ability and their pattern of autistic symptoms, no single type of educational placement can meet the needs of all (see Parsons et al., 2009; 2011). Moreover, unless adequate help is provided, children with autism in mainstream schools might experience isolation, rejection and bullying. The risk of school exclusion in this group is particularly high relative to children with other types of SEN (Batten et al., 2006). Thus, in practice, a range of different options is necessary.

Types of educational placements

1. mainstream without support;
2. individual support in a mainstream classroom;
3. resource bases (or 'units') specialising in autism or communication disorders attached to mainstream schools. These provide pupils with the opportunity to mix with their typically developing peers as well as providing specialist support and education as needed;
4. schools specifically for children on the autism spectrum;
5. special schools for children with a variety of educational needs due to intellectual impairments or emotional and behavioural difficulties;
6. residential schools for children whose needs cannot be met in day provision (often because of severe behavioural or emotional difficulties, or the family's needs). These may be for children with autism specifically or for children with varying needs;
7. independent or non-maintained schools funded by the local authority if no other appropriate options are available or in some cases paid for privately by parents;
8. home schooling (generally chosen by parents who want to follow a home-based programme or who do not feel local provision is appropriate or when their child has been excluded).

Which type of placement best meets the needs of a child on the autism spectrum will depend on his or her individual skills and difficulties, as well as the family situation. All schools vary widely in quality and expertise in educating pupils on the autism spectrum and careful assessment of both the child and the school is needed in order to maximise the chances of a successful placement.

[2] For a more comprehensive review see the AET report on "Educational Provision for Children and Young People on the Autism Spectrum Living in England" by Jones et al., 2008

2.3 Autism in adulthood

There has been a recent trend to invest heavily in good evidence-based specialist education for children and young people with autism, but less so in adult services. It is an obvious, though rarely considered, fact that we are adults for many more years than we are children. On average, UK citizens will be adults for approximately 60 years. Services for adults, therefore, need to be planned to cover a much longer period of an individual's lifespan and respond to their needs arising at different stages of adulthood. A survey published by researchers at the University of Leicester in 2011 estimated that prevalence of autism in adulthood is approximately the same figure as that estimated for children: 1% (see Brugha et al, 2011).

In December 2010, the UK Government published a statutory guidance for English local authorities and National Health Service organisations to support the implementation of the Autism Strategy as required by the Autism Act, 2009, entitled *Implementing "Fulfilling and rewarding lives"*. This provides statutory guidance on how to help adults on the autism spectrum to be fully included and supported within society. In particular, adults on the autism spectrum must be provided with a diagnosis if this is felt to be of benefit and to be able to access support if they need it. They have a right to expect that mainstream public services will treat them fairly as individuals, helping them make the most of their abilities.

The Autism Act 2009 states that:

- all individuals with autism have a right to a community care assessment, regardless of IQ;
- local authorities and the NHS have a duty to provide autism awareness training for all staff and specialist training for key staff, such as GPs and community care assessors;
- local authorities must develop a clear pathway for the diagnosis and assessment of adults with autism and commission appropriate services based on adequate population data and ensuring that the views of adults with autism and their carers are taken into account in the development of services locally.
- To ensure that these objectives are met there must also be an autism lead in each local area to liaise with local services.

The importance of the above objectives was elicited through the extensive research recorded in the National Audit Office Report "Supporting people with autism through adulthood" (2009). Findings from this report indicated the lack of adequate provision for adults on the autism spectrum nationally and, in particular, the challenges faced by individuals without additional learning difficulties in accessing any type of support, or even in being able to obtain a diagnostic assessment.

Research studies of adults with autism have also reflected the generally poor outcomes, in terms of employment, living and social integration. According to the National Autistic Society, only 15% of adults in the UK are in full-time employment; just over half of adults in the UK have spent time without a job or benefits; and at least a third of adults with autism report experiencing severe mental health difficulties due to a lack of support.

In a recent systematic review of research studies on adults with autism (mainly of individuals in their late teens to early 40's), conducted between 1960 and 2010 (Howlin & Moss, 2011), it was estimated that fewer than 25% of individuals were assessed as having a 'good' to 'fair' outcome. For most, outcome was rated as 'poor' or 'very poor'. Of note was that outcome in cohorts studied over the last decade was no more positive than that of cohorts followed up during preceding decades.

Of growing concern is the lack of information on the needs of older adults with autism. Almost all current adult outcome studies have focused on individuals in their 20's to 40's. Knowledge about the ageing process in autism is almost non-existent and systematic information about the social, emotional, physical, and mental health needs of elderly people with autism is lacking. It is also evident that many individuals remain highly dependent on their families well into adulthood. How they will cope when parents are no longer able to support them is a further issue with major implications for society as a whole.

3. Research methodology

The research team used a mixed-methods approach:

- First, we conducted a literature review of research and policy documentation in the field of autism, educational planning and outcomes.
- Second, we collected quantitative and qualitative online survey data from key stakeholder groups.
- Third, we collected opinions and examples of practice in greater detail via focus groups and interviews.

Ethical approval for this research was received prior to commencement of data collection from the University of Birmingham's Research Ethics Committee (Reference: ERN_10-1287).

The section below sets out the different methods we selected and some summary statistics (e.g., number and geographical spread of survey respondents).

3.1 Literature review

The literature review centred on collecting evidence from research studies, practitioner reports, and policy documentation. The three main questions above (Section 1.2) were the key drivers to identifying relevant publications and the themes for each of the three key questions were expanded upon to guide collection of relevant documents.

Much of the literature review was based on existing systematic reviews undertaken for other purposes. For example, in terms of Question 1 on "defining good adult outcomes", the search relied heavily on a systematic review conducted by Howlin and Moss (2011) of the existing literature. In addition, a systematic search for follow-up studies on adults on the autism spectrum was conducted using the search terms: follow-up; outcome; adult; autism; ASD; Asperger syndrome. Any additional studies included in a previous review by Howlin (2004) were also examined. For the review that focused on assessment and educational planning, we revisited the publications included in the Parsons et al., 2009; 2011 international literature review, commissioned by the National Council for Special Education, Ireland. This report combined a systematic literature search of empirical studies with expert guidance in order to review 'best practice educational provision for best outcomes' for individuals on the autism spectrum. In addition, we included single case studies and updated the search, using the same criteria, to include papers published between 2009 and 2011. Key practice and policy documentation was selected as part of the review around educational planning, target setting and assessment in schools. Within these documents a systematic review was conducted to extract those key components in terms of educational policy, practice guidelines and recommendations.

3.2 Online surveys

Online surveys were designed by the project team to collect data from key stakeholder groups in a quick and efficient way. As much as possible the use of online surveys would allow collection of data from a wide range of individuals with autism, parents, teachers and other practitioners in England. Taking into consideration the 'digital divide', it is worth noting that the data collected as part of this research was biased towards those who have access to email and the internet. The questions in each survey were decided upon through consensus opinion by members of the project team, with every effort to make them both broadly relevant to the key questions guiding this research and easy to understand. Because of the time constraints imposed on this project, there was only limited piloting of these surveys before they were uploaded onto the AET website. The online surveys were live and available for completion between 11th April and 15th May 2011.

Surveys for five stakeholder groups were written and uploaded:

1. **Children and young people on the autism spectrum**
2. **Adults on the autism spectrum**
3. **Parents of children on the autism spectrum**
4. **Parents of adults on the autism spectrum**
5. **Practitioners working in schools or colleges**

Individuals from these groups accessed the surveys through a dedicated AET webpage, read a front page describing the purpose of the study, and ticked a box to agree to participate. All data collected were anonymous, with no names, date of birth or other identifiers collected. The software used was called iSurvey, a survey generation and research tool for distributing surveys and collecting data.

A detailed description of all the surveys designed for this research project can be found in Appendix 1.

3.2.1 Description of how the survey was circulated

Several large scale 'networks' were included to disseminate the surveys, including:

- NAS and AET mailing lists
- DASLne (Database of children with Autism Spectrum Disorder Living in the North East) – a registry for parents of children with autism in the North East of England
- PLASN (Pan-London Autism School Network) – for teachers of special schools in London and the home counties
- SENJIT (Special Educational Needs Joint Initiative for Training) mailing list
- Autism West Midlands – information included in their March Newsletter
- Ambitious About Autism website; Talk About Autism discussion board
- Autism Centre for Education and Research (ACER) regional tutors (including teachers, SaLTs, SENCos, OTs and parents).
- Sussex Autism Society
- Nottingham Regional Society for Adults and Children with Autism
- Autism practitioners through the Priory Education Services
- National Association of Disability Practitioners
- Royal College of Speech and Language Therapists web based discussion group
- Speech and Language Therapy London Special Interest Group in Autism Spectrum Disorders email discussion group
- ABA-UK email discussion list
- id-research-uk jiscmail discussion list

Most of these network contacts received a letter of invitation to take part as well as the link to the AET Outcomes Project website. It was expected that there would be a "snowballing" effect as those targeted through the network shared information on the surveys with their colleagues and other contacts. In addition, the AET generates significant traffic to its website and there was an icon on the home page linking directly to the AET Outcomes Project page. The National Autistic Society also posted information about the study and the surveys on its website. Finally, the project team directly contacted key individuals, schools and services known to them.

3.2.2 Responses to the online surveys

Overall, 900 people from all except two[3] English counties and boroughs responded to the surveys. Not all respondents fully completed the survey, but for the majority of survey responses we were able to extract data from partially completed surveys as well.

The surveys were completed (or partially completed) by:

- 30 **young people on the autism spectrum (aged 18 years or below)**
- 69 **adults on the autism spectrum**
- 382 **parents of children and young people on the autism spectrum**
- 70 **parents of adults on the autism spectrum**
- 349 **practitioners** working in schools and colleges.

[3] There were no respondents from North Humberside and South Humberside

3.3 Focus groups

Focus groups are essentially 'group interviews', and are a very commonly used method in social science research (see Bloor et al., 2001). They are an open-ended discussion guided by a moderator with a small group of people who have a particular role, perspective, or involvement in the topic of interest (typically made up of 6-12 individuals).

Focus groups are very good for gathering a range of views or experiences from the participants. Importantly, the purpose of the focus group is not to aim for consensus but to provide a voice for all members of the group. This approach can be inclusive and empowering for participants because it provides an opportunity to share meaningful experiences, which can reveal new insights for others taking part in the group discussion. Collecting qualitative data through focus groups was therefore an ideal method for this research project, which aimed to generate detailed responses as well as broad overviews of key issues from a range of informants.

A general protocol for the focus group data collection was agreed upon by members of the project team and can be found in Appendix 2. Focus groups were relatively small in size, with an average of 4 people (ranging between 3 and 8 participants) and typically lasted approximately 1.5 hours. 35 parents, 4 young people with autism, 17 adults with autism and 17 practitioners working in schools took part in in-depth focus groups within a range of contexts including: autism specialist provisions at preschool, primary and secondary levels; mainstream primary and secondary schools with an autism resource base; general special schools; an adult employment support group; adults in supported accommodation.

Notes were taken during all focus groups and some were also audio-recorded (with permission from the participants) and transcribed in full or semi-transcribed (i.e. some sections were transcribed and for other sections only summary notes were taken). The audio recording was deleted once the transcription was made and no participant could be identified from the transcription or other notes.

3.4 Interviews

As with the focus group data collection, interviews were conducted to gather personal accounts and opinions on the key questions related to this project. This is an important addition to the methodology as some respondents may feel more comfortable communicating individually rather than in a group situation. Furthermore, for some stakeholder groups there may have been only one or two representatives identified. Finally, some respondents lived a distance away from members of the project team and in these cases phone interviews were arranged.

A total of 46 interviews were conducted with a range of stakeholders, either face to face or via phone. Interviewees included adults on the autism spectrum, parents, practitioners, educational service providers, commissioners, regulators and academics.

The interview questions varied depending on the nature of the respondent but overall the three core themes outlined in Section 1.2 above guided the composition of questions. Open questions were chosen to elicit rich narratives from the interviewee rather than closed 'yes' or 'no' responses.

For most interviews, notes were taken by the member of the project team talking to the interviewee on the phone, but some interviews were - with explicit permission of the interviewee - audio-recorded and semi-transcribed. All audio recordings were deleted following transcription.

3.5 Overview of data analysis

3.5.1 Survey data

From the survey data, summary statistics were calculated based on the responses given. These statistics were either percentage responses or number of responses out of a total number of respondents. Based on participants' ratings of certain questions (on a 5-point Likert scale), percentages of agreement or disagreement with a statement were calculated. For the data analysis, the 5-point scale was converted into scores from 1-5 with 5 representing the most positive end of the scale.

Open-ended questions from the surveys were analysed using a content analysis procedure (Stemler, 2001). Content analysis is used to categorise qualitative data. First, coding tables were developed by systematically examining each response and either creating a new (sub) category or assigning the response to an existing category. Once the coding tables were agreed upon and finalised (after discussion within the research team), each response was assigned a code (e.g., for the parent survey, "to be toilet trained" and "learn some cooking skills" were both coded into category "1- Independence", and specifically into sub category "1.1- Develop a specific life skill").

3.5.2 Focus group sessions and interviews

The data from focus group sessions and interviews were analysed for each group of participants (children, adults, parents, practitioners) separately using content analysis. Particular themes were independently extracted and then paired members of the team met to reach a consensus agreement on the key thematic outputs. These items were tabulated to allow for thematic comparisons to be made within and across stakeholder groups.

3.6 Limitations of this research

As with most research studies, there were methodological limitations that need to be considered when interpreting the findings outlined in this report. The most significant limitation was the challenge of consulting a representative sample of stakeholders. Efforts were made by the study team – as outlined above – to collect data from a large number and a broad range of stakeholders, and from a good geographical distribution, but despite these efforts the data below only represent the responses of a section of the community. In particular, given the time constraints and the need to properly prepare methodologies for good data collection, it was only possible to ascertain a small amount of data from individuals with autism who have additional learning difficulties. Surveys were written in language that was accessible to individuals of varied educational level and a small number of focus groups and interviews were conducted with young people and adults who have autism and a learning difficulty. However, data were not collected from people with autism who do not use speech as a means of communication. As all surveys were written in English, this meant that individuals who could not read or write English were unable to provide responses. The surveys of adults with autism were predominantly completed by individuals with a diagnosis of Asperger syndrome, skewing the findings from this section towards the opinions of individuals from that part of the autism spectrum.

4. Defining good adult outcomes

4.1 Literature review

Searching for a definition

In terms of the current research literature that has explored outcomes for adults on the autism spectrum, most studies have assumed that a positive outcome means living independently of family, having paid employment, and having friends and close relationships. Indeed, these criteria for what constitutes a good outcome may well be true for a certain percentage of individuals with autism. Ratings of 'good', 'fair' or 'poor' outcomes in most of the studies reviewed by Howlin and Moss (2011) are closely based on these domains, and thus any individual still living at home, or in residential settings, and/or without work are deemed to have a 'poor' or even 'very poor' outcome. However, it is important to note that meeting the above criteria for a good outcome is not necessarily what all individuals with autism want or need. For example, independent living, without adequate support, can result in a life that is lonely, isolated and devoid of interest and stimulation; employment commensurate with intellectual level can result in intolerable levels of stress, especially if there are excessive demands on flexibility or social skills. Moreover, not all individuals on the autism spectrum want close friendships or a social network. These possible differences in what a person with autism may regard as a good outcome compared to someone without autism means we must be cautious about the assumptions we make on behalf of adults for what they should be achieving in adult life.

Studies of quality of life in adults with autism are rare. In one of the very few studies of factors related to quality of life, Renty and Roeyers (2006) suggest that one-dimensional measures do not adequately reflect outcome. Instead, they found that the discrepancy between needed and received levels of formal support was most strongly associated with quality of life. Billstedt, Gillberg and Gillberg (2011) also found that access to regular recreational activities was more strongly related to quality of life than occupation, or type of accommodation.

In a long-term follow-up of individuals aged from 16 to 60 years (Howlin et al., in preparation), the wish of many individuals and their families was not necessarily for independent accommodation, but for a range of residential settings that offered space, security and stimulation, with support as and when required. In particular, concern that there might be no adequate services to care for the individual with autism when parents were no longer living was a major source of anxiety for many. Although the majority of adults wanted employment of some sort, many felt that they could not cope with full time work, or with jobs that made too many demands either intellectually or socially. Jobs that were part time, routine and which did not require too much social involvement were what many were seeking, even if such work seemed too low a level for their intellectual ability. With regard to close friendships, although some individuals wished for such relationships, or marriage and a family, they were in the minority. Not all wanted friends, or the demands that close relationships entail, and encouragement to be more sociable, no matter how well meant, was often considered far from helpful.

One of the few individuals in the Howlin et al. (in preparation) study who was rated as having a 'very good' outcome was a middle aged woman in a residential home who had limited autonomy, and no close friends. However, the home had excellent facilities, close links to the local community, and offered access to many different outside activities. Although far from independent, she was obviously very happy and extremely well settled. In contrast, a man living independently in his own flat was rated as having a 'poor' outcome as the accommodation was dirty and shabby; he had no social contacts apart from occasional visits from his brother and his life generally was very restricted and unstimulating. A striking outcome of this study was the expressed wish that "neurotypicals" would stop imposing upon them their own views of "a good life".

An important issue in terms of defining good outcome is the sequence of events (or shorter-term outcomes) that lead to good outcomes in adulthood. A further question is whether there is ever a natural "stopping point" where a person says that they have reached that target outcome. Take, for example, employment. An often targeted outcome from school is achieving reasonable qualifications or grades, which are then used either to help find employment or to meet the requirements for being accepted on to a further education course. Once someone has been in employment for a period of time, they may look to improve their job prospects, receive a promotion or maybe increase their salary. So what is the final good outcome from this sequence? Being the top of your field? A sense of achievement? Feeling that your job contributes to society? The outcome will vary over the period that a person is employed and may depend

on other outcome factors that have occurred during that time (e.g., having a family may mean work becomes less important).

So what is education trying to achieve in terms of outcomes for when children with or without disabilities leave school? The policy document Every Child Matters initiative launched in 2003 specified five main outcomes for children and young people:

Every Child Matters

1. Being healthy
2. Staying safe
3. Enjoying and achieving
4. Making a positive contribution
5. Achieving economic well-being

It was noted that these outcomes should be the objective of educating a child or young person "whatever their background or circumstance".

The Every Child Matters initiative, which led to the Children's Act (2004), was guided by the principles of Outcome-Based Accountability (OBA), a model pioneered by Mark Friedman (2005). The OBA model starts with defining what the end-point is or what *outcomes* we are trying to achieve for a specific population. Outcomes within the OBA model are conditions of wellbeing (e.g., points 1-5 from Every Child Matters above). Once these outcomes are identified then *indicators* should be set as a means of measurement (e.g., number of people in employment). *Baseline measures* are put in place to compare progress over time for each of the indicators. These baseline measures also allow those conducting the OBA to look at what underlies these data (e.g., what is the nature of services being delivered? How are staff trained?). Then an action plan or recommendations of change are set out to better meet the desired outcomes and ongoing measurements of success are put in place. The OBA model has provided a useful structure in numerous national and local contexts to assist in the planning of services to meet well-defined outcomes.

There are several important recent documents where in part the directive was to look at outcomes for pupils with special educational needs. The Achievement for All document (DCSF, 2009) aims to improve outcomes for children and young people. It focuses on pupils with special educational needs and disabilities (SEND), though it is anticipated that it will provide a model for different groups of young people within the context of the whole school. Its aim was to:

"Support 460 schools, in ten pilot local authorities, to implement and share the best inclusive practice for improving outcomes for children and young people with SEN" (p.3).

One of the approaches recommended within the document looks at effective practice to improve the wider outcomes for children and young people with special educational needs. There are five areas of focus for strand three of the wider outcomes:

Achievement For All

1. Improving attendance
2. Improving behaviour
3. Eliminating bullying
4. Developing positive relationships with others
5. Increasing participation in extended services provision, including extra-curricular activities (p.42).

The Lamb Inquiry (2009), which investigated ways to increase parental confidence in the SEN assessment process, indicated that in order to ensure a clearer focus on the outcomes and life chances for children with SEND, a *'radical recasting of the relationship between parents, schools and local authorities would be needed'* (p.2). The report states that there needs to be change in four key areas:

Lamb Enquiry

1. Children's outcomes at the heart of the system
2. A stronger voice for parents
3. A system with a greater focus on children's needs
4. A more accountable system that delivers better services

Despite debates over issues of measurement and definition of what constitutes a good outcome, it is evident that, compared with their peers of similar age and intellectual level, many adults on the autism spectrum are not receiving the opportunities they should be offered. The report by Brugha and colleagues (2007) on adults with autism living in households throughout England, has highlighted high levels of social isolation amongst this group, with the majority having low educational attainments, being

without a partner, living in supported housing, and being under-supported by social, employment, educational, welfare or health services. Howlin and Moss (2011) also found that almost half the individuals (aged 16-60) in the studies reviewed were still living at home and only 46% were in employment (regular, supported or sheltered) or full time education. For those in work, jobs were mostly low level and poorly paid. Only 15% of individuals in the studies reviewed were reported to be (now or in the past) in a long term sexual relationship, although around one quarter did have at least one friend.

In summary, there seems to be some consensus as to what we define as good adult outcomes in general terms, but it may well be that individuals with autism are looking for different outcomes than are currently set out in the educational, research and policy literature. Clearly one of the overarching issues is that "good outcome" has no single definition and so a person's individual choice must be at the centre of any planning for educational and adult-life services. We must, therefore, turn to the stakeholder community and in particular to individuals with autism themselves to tell us what outcomes they want to achieve and how education can meet these objectives.

4.2 Consultation data collection and analysis

The sections below outline data collected from stakeholders on what they felt should define good adult outcomes for people with autism. Data was also collected on what the current situation for adults on the autism spectrum is, to compare preferred with actual outcomes.

4.2.1 Survey for adults on the autism spectrum

The questions in this survey attempted to address important aspects of the lives of adults on the autism spectrum with respect to the seven adult outcomes referred to in *'Our Health, Our Care, Our Say'* (Department of Health, 2006, p.42), and which align/overlap considerably with the priority areas of *'Fulfilling and Rewarding Lives: the strategy for adults with autism in England'* (Department of Health, 2010). Both sets of criteria are summarised in Table 1 below. Whilst we were not able to cover any of these key aspects in much depth due to the need to keep the survey a reasonable length, they were nevertheless used to help design our questions addressing enablers and barriers to good outcomes for this respondent group.

Table 1: Priority areas / outcomes from recent government policy initiatives

'Our Health, Our Care, Our Say' (DoH, 2006): adult outcomes	'Fulfilling and Rewarding Lives' (DoH, March 2010): priority areas
• Improved health and emotional well being • Improved quality of life • Making a positive contribution • Choice and control • Freedom from discrimination • Economic well being • Personal dignity	• Having a right to receive an assessment of need from social services • Getting the same opportunities for education and further education as everyone else • Being supported to get a job and stay in work • Being able to choose where to live – just like anyone else • Having relationships and social networks • Having their health needs properly met in a way which is appropriate for someone with autism • Receiving support to live independently, as appropriate

A total of 69 adults on the autism spectrum aged 17-59 (average = 34 yrs and 3 months; median = 32 yrs) started the survey although not all of them finished it; therefore, the number of respondents varies across the questions summarised for this group.

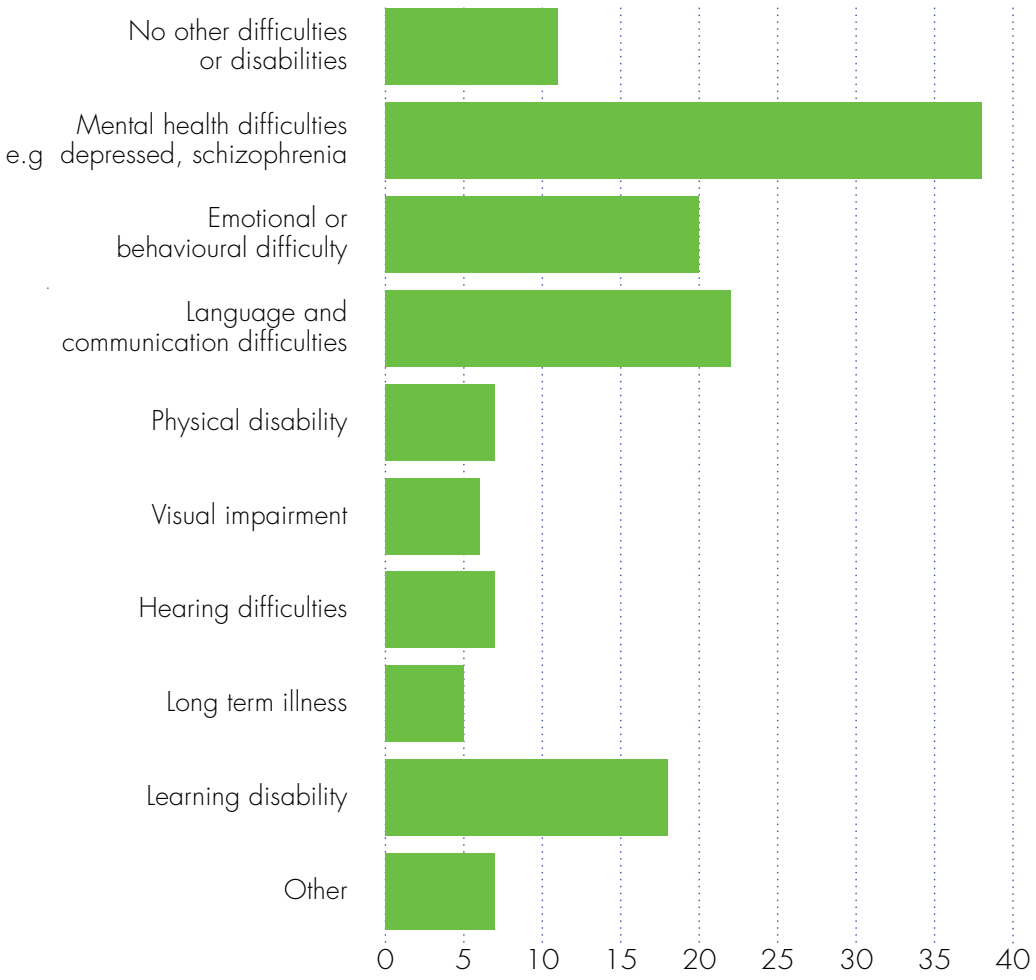
Of those starting the survey 46% (32/69) were female and 54% (37/69) were male.

81% (54/67) had a formal autism spectrum diagnosis and of the 37 who went on to specify, a majority (81%) were diagnosed with Asperger syndrome. Most (35/54; 65%) were diagnosed in adulthood, with 10 (18%) diagnosed in adolescence and 9 (17%) as a child.

More than half of the 69 respondents (38; 54%) reported that they had mental health difficulties; 22 (31%) reported language and communication difficulties; 20 (29%) indicated emotional and behavioural difficulties; and 18 (26%) said they had a learning disability (see Figure 1)

Figure 1. Nature of 'additional difficulties' reported by the adult survey respondents (N=69)

Do you consider yourself to have any other difficulties or disabilities (formally diagnosed or not)?



When asked to rate current satisfaction with different aspects of their lives (1= least positive; 5= most positive; 3= not really sure), the adult survey respondents (N=54) were, on average, least satisfied with their current work situation (average = 2.46); the support they needed to help find a job (average = 1.96) and support to stay in a job (average = 2.14). Figure 2 shows the percentage of agreement or disagreement with each of the statements.

Figure 2. Percentage of respondent's agreement with statements regarding current satisfaction with aspects of their adult life (N=54)

Although respondents were more positive about where they were currently living (average = 3.48), and that they had had a choice about this (average = 3.42), they were less satisfied with the support they had received to help them find somewhere to live (average = 2.34).

Respondents were also less satisfied with the support available from doctors (average = 2.83) and were clear that having an autism spectrum condition had hindered them from doing some of the things they wanted to in life (average = 1.51).

Despite this, however, respondents were generally positive about the opportunities they had had to meet people and make new friends (average = 3.35) and satisfied with their personal relationship(s) (average = 3.20).

They also acknowledged, on average, that having autism had helped them to do some of the things they wanted to do in life (average = 3.46) and that other people's understanding about their autism had made a difference to them being able to do what they wanted to do (average = 3.45).

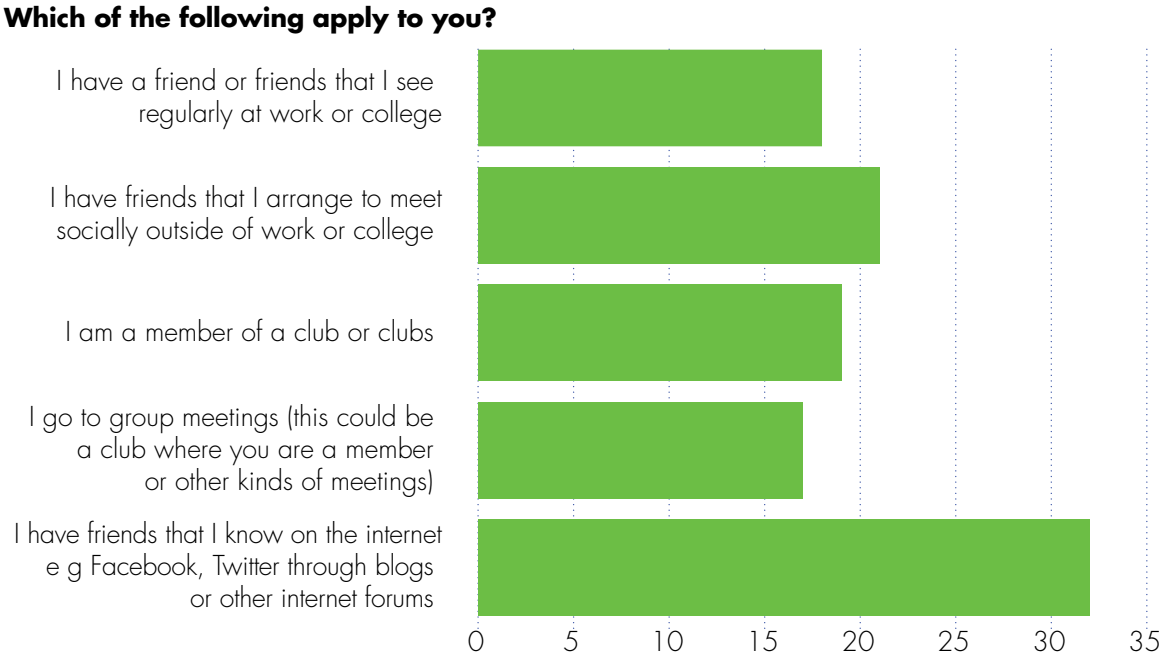
In terms of the current situation with regard to employment, education or training (total number of respondents = 59) only a quarter (24%) of the adult respondents were employed in a full-time job without any support; although a further 10 people (17%) were also in full-time work, with some support. The largest proportion of the group (36%) reported that they were not currently in any employment or education.

Thirty-three of the 54 (61%) adults who provided a response to this question were in receipt of benefits, the most common of which was the Disability Living Allowance (34%) followed by tax credits (13%). Small numbers of respondents indicated that they received other benefits including housing allowance (11%); incapacity benefit (10%); and income support (10%). People with a formal diagnosis were twice as likely to be in receipt of benefits (N=28) than if they did not have a diagnosis (N=14).

Most respondents were either currently living in rented accommodation (32%) or in an owned / mortgaged house or flat (45%); and tended to live with other people – i.e. a spouse/partner (26%); parents (24%); their children (20%); other family members (10%).

In terms of personal and other social relationships, 51% said they currently had a partner but only a minority seemed to have social networks that extended beyond their personal relationship. 74% said that they did not have a friend/ friends that they saw regularly at work or college and 70% did not arrange to meet friends socially (outside of work or college). A minority (27%) said they were a member of a club or attended group meetings of some kind (24%). A larger proportion, however, indicated that they had friends that they know or meet on the internet (46%); see Figure 3 for a summary of these data.

Figure 3. Social involvement in different settings for adult respondents (N=69)



The final 'open' question where respondents could add anything further if they wished to, provided 33 written-in comments and, without exception, these focused on areas where people felt they had been let down and / or more support was needed. These areas were particularly around awareness and other people's knowledge of autism and the need for more professional training:

"There is so little support for Aspergers (adults) in U.K. it is amazingly (bad)..... Training should not just be for teachers or regarding children, but for adults too and for ALL professionals (social services, NHS staff etc). "

There was particular frustration about the lack of support generally for adults on the spectrum, for example with life and social skills:

"More support to access mainstream activities or skill building classes. More ASD groups so I can have a life with people like me."

There were also comments about specifically coping with autism as an adult and the challenges that brings when services are not equipped to provide appropriate support:

"The plight of children with autism is highlighted but the plight of adults who have grown up in a world with no help with their condition has not been addressed. Why are we an ignored group?"

"There is zero attempt at re-skilling or teaching social skills. The NHS does nothing - it has a Learning Disabilities unit so the normal GP has to refer me to them but they say they are only funded for the under 75 IQ people and refuse to take me on."

4.2.2 Focus groups and interviews with adults on the autism spectrum

Twenty adults were consulted as part of focus groups and interviews (age range 18-64 yrs, average age 31); there were two female participants; four adults were interviewed over the phone. Participants were asked about their current situation, their experience at school and about what they would like to achieve during the rest of their adult life.

Five participants in focus groups were attending college and doing entry level courses (e.g., cooking; gardening; drama); three others were completing more advanced college courses (e.g., learning business skills) and four were in higher education. Only two of the adults were in paid employment (one of them working part-time) and one focus group included adults attending a specific course supporting people on the autism spectrum into work.

Their living situation varied with some still living at home, others in residential settings and five of the participants living independently.

Many of the participants had only been diagnosed as adults and they commented on the difference their diagnosis had made for them and the importance of knowing early on:

"Knowing about my diagnosis has really helped as I get support. Being able to tell people what is different about me makes a huge difference."

"Parents need to be open to their children about the diagnosis. They need to tell them as early as possible as there is no benefit from finding out later in life as it is harder to get help."

One idea that was brought forward several times across interviews and focus groups was for young people on the autism spectrum to have the opportunity to meet an adult on the spectrum **"who's been there, done that"** and who can reassure and inspire them.

The groups were asked about their aspirations for the future and most of them focused on their desire to be in employment. One focus group ranked what they would most like to achieve and 'having a job' was their top priority.

"I'd like to have a job of some description. The most important aspect of a job for me would be lack of stress though. I would much rather have a job that is not stressful, even if it wasn't well paid than the other way around."

Another participant felt that before he was ready for employment there were a number of aspects of his life he needed to work at and resolve before being ready for the work place:

"[I would like to work] but there are other problems I have to overcome first. Which are more to do with understanding the world I live in... have relationships with people... get out of my depression. I'm aware that I get manipulated a lot and now I'm trying to understand my own agenda, what I'm good at and what I have difficulties with."

Some of those who had been in employment felt there was little direction in their career path and that they had either drifted from one job to the next; or they had stayed in a job that was not appropriate for them for too long as they were not aware of any alternatives or progression pathways.

One focus group with adults on the autism spectrum living in residential supported accommodation for people with learning difficulties and who were aged between 30 and 50, listed a number of desired future outcomes which were more about developing independent living skills and forming relationships. In terms of learning daily living skills; these included:

- knowing how to read and write;
- be able to go out alone (e.g., go shopping or go to the pub);
- know how to use money;
- being able to travel independently (e.g., know how to cross the road safely and how to use public transport);
- know how to behave with other people properly and be able to control emotions and anger (especially in public situations);

When asked to list where they would like to be living in the next ten years, 4 out of the 5 participants, were hoping to move out of residential care and into the community, living either **"in a flat on my own"; "in a flat alone", "close to my parents"; "with a girlfriend"** or with some support **"in a house with a support worker who is smiley and we keep the house nice and clean".**

Other themes brought up in this particular focus group were to understand their own emotions better and to control them when they get out of hand. This included for example, **"trying to shout less and not destroy others' property"; "learn to use a 5-point scale to understand my level of anger"; "learn strategies to understand how others feel"**. Being more self-confident and less anxious was also highlighted as a priority goal.

4.2.3 Focus groups and interviews with young people on the autism spectrum

Sixteen children and young people aged between 6 and 16 years were seen either individually or within a small group. We initially suggested to participants, their teachers and their families, that the interviews would be conducted together with other children but several children requested instead to be interviewed on their own. All were being educated in 4 maintained primary and secondary mainstream schools within London and Oxfordshire, either within an Autism Resource Base (ARB) or accessing mainstream provision on a full-time basis.

To begin, our interviews and focus groups concentrated on eliciting what children and young people valued in their life right now. This approach has been used previously (Beresford et al., 2007), and was especially appropriate in the current context since difficulties with future-oriented thinking is characteristic of autism (Jackson & Atance, 2008). This approach was successful in getting children to express valued aspects of their current lives and their hopes and aspirations for the future. Nevertheless, and perhaps unsurprisingly, the resulting data were much more limited in scope than the data obtained from parents and other stakeholders.

Valued aspects of children's current lives

The majority of children discussed the importance of relationships with other people, including their families, friends, and teachers at school. All children talked positively about their friendships, which included, for the most part, one-to-one interactions with peers with autism (within the ARB) and sometimes with peers within the mainstream school. Children generally expressed a strong desire to have friends, although difficulties establishing and maintaining their friendships was apparent in several discussions with children and young people. Several children noted that their difficulties fully understanding or "getting" social situations often impacted upon their peer

relationships. One 15-year-old boy from a secondary ARB also said:

"A friend is someone who doesn't exclude me because of my autism. Like [boy from mainstream], he doesn't exclude me, he is a nice guy ... but most of the kids in the mainstream exclude me."

For those children who spoke about their autism explicitly, these discussions were largely negative. Children would "rather not have it" for several reasons: (a) "life would be easier", (b) they would get less frustrated with friends, family, and teachers, (c) it would be "easier to understand people", and (d) it would make it easier for them to learn. For those children who did not mention their autism openly, these children were nevertheless deeply aware of "being different" or "having lots of things wrong" with them. These negative remarks were made largely by children in upper primary or lower secondary school, while older children seemed to be more accepting of their condition. The students interviewed from an upper secondary school ARB were aware of their difficulties with coping with the demands of secondary school (e.g., transition times between classes, lots of homework, and too much to process during class) and GSCEs but the tone of the discussion was less negative than the discussion with younger children.

Hopes and aspirations for the future

Generally, children's responses to questions relating to their ambitions and aspirations for the future reflected the sorts of outcomes one might expect to see in children without autism: to have a boyfriend or girlfriend; to get married and have children; to go to college or university; to have a (often well-paid) job. All children noted their desire to live independently – sometimes on their own and sometimes with a partner – and many remarked on missing their family, reflecting a deep bond with their parents, siblings and grandparents.

"I might want to live alone but I might then miss my family. I only want to get married if I find the right one."
[15-year-old boy in secondary ARB]

All children said that they would like to have a job in the future, which usually revolved around their talents or interests. Several children commented on their desire to have a family, and that they would continue to enjoy spending time with their family (including their parents) when they get older.

4.2.4 Survey for parents of individuals on the autism spectrum

Parents of children and young people on the autism spectrum

Parents were asked about what hopes and aspirations they had for their child in the short term and the longer term: (1) *What I would like my child on the autism spectrum to have in his/her life in the next 12 months is…" and (2) "What I would like my child on the autism spectrum to achieve or have in his/her adult life* is…". They were given three response boxes for both questions where they could indicate three 'top priorities' in no particular order. Of all 382 parents of children and young people, 327 responded to these questions, not always filling out all three response boxes, leaving a total of 985 responses for question (1), and 931 responses for question (2).

The top priority for parents of children both over the next twelve months (21%) and when their children are adults (25%) was building social relationships. Within this social relationships domain, in the next twelve months parents' main priority is for their child to develop social skills (10%), but when their child is an adult their priority is for them to have meaningful relationships (6%). A parental priority for adulthood but not in the short term in childhood is for their offspring to have a girlfriend/boyfriend, a family of their own and to be accepted by the community.

As would be expected, education was a short term priority for this group of parents of children with autism (27%) and employment was a priority for when their children become adults (22%). Education priorities in the next 12 months were for their children to achieve academic skills and make academic progress (9%), to cope with and enjoy school (5%), and to get the help needed/a proper understanding from school (4%). In terms of work during adult life, parents' main priority was that their children have a meaningful job (11%) or just more generally a job (8%).

Independent living skills were seen as more of a priority for when their children become adults (19%) than in the next 12 months (11%). In the next 12 months the main priority of parents of children with autism was that their child could organize themselves more and make arrangements with friends (21%), whereas for when they are adults the priority was more generally become more independent (16%).

Finally, parents of children with autism held emotional wellbeing as a priority in the next 12 months (18%) and even more so in adult life (25%). More specifically, being happy was reported frequently for both childhood and adulthood, and "reaching their full potential" when they are adults.

For further detail on parent's response pattern to these questions please see Appendix 3.

We also explored statistical associations between parents' hopes and aspirations and their child's age. For aspirations in the next 12 months, parents of younger children were more likely to indentify language skills as an important goal for their child but less likely to identify their child's emotional well being as a short term priority than parents of older children. In terms of hopes/aspirations for their child in their adult life, parents of younger children were more likely to identify socialisation and relationships as important and less likely to identify non-educational provision as important when compared with parents of older children.

Parents of adults on the autism spectrum

Of the 70 parents of adults on the autism spectrum who completed (or partially completed) the survey, 19 had children with a diagnosis of autism (of which 9 had an additional intellectual disability). Thirty-five parents had children with a diagnosis of Asperger syndrome, three had children with high functioning autism, and two with PDD-NOS. Three classified their children as having an 'other' diagnosis, which included a diagnosis of semantic-pragmatic disorder. Diagnostic information was missing for 8 participants.

When asked about qualifications gained by the adult offspring with autism (see Table 2 in Appendix 3) the largest percentage (27%) had no qualifications, followed by 20% of individuals who had up to four state qualifications (e.g., GCSEs). The next largest percentage was those with undergraduate degrees (16%). There were missing data on 13% of those contributing.

In terms of the current work status of their offspring with autism (see Table 2 in Appendix 3), parents reported that the largest percentage (33%) of their adult children were studying at college or university. 27% of adults were neither in work nor education. Very few (4%) were receiving any type of support to do work or voluntary work. There were missing data on 12% of respondents. Statistical analysis revealed that there was no association between the age of offspring with autism and either type of qualifications, nor current work/education status.

Parents of adults on the autism spectrum were asked about what aspirations they had for their son and daughter in the short term (next 12 months) and the longer term (the rest of their child's adult life). They could indicate their three 'top priorities' (in no particular order) in separate text boxes. 53 parents completed this section of the survey, but not all parents completed all three response boxes, leaving a total of 154 responses to the question on short term and 144 responses on longer term hopes and aspirations.

Parents' top priority for their adult offspring in both the short term (25%) and the long term (30%) was to build social relationships. This included forming meaningful friendships in both the short (9%) and the longer term (10%). "A social life" was seen as more of a priority for the short term (8%) than the longer term (3%) but having a girlfriend/boyfriend, starting a family and being accepted by the community were seen as longer term priorities than shorter term (for further detail on parent's response pattern see Table 3 in Appendix 3).

Their offspring's work life was a strong short term (22%) and long term (17%) priority for parents of adults on the autism spectrum. In the shorter term 10% of parents are interested in their child simply being in a job compared to in the longer term (0%). Parents are more likely to identify a longer term objective that their children gets a meaningful job they enjoy (13%) compared to the short term (3%). A shorter term priority is that their children complete educational courses; this was not seen as a longer term priority.

Another priority for parents of adult children was their child's independence, which was reported for both the short (19%) and long term (17%). In the shorter term, the clear priority was to learn a specific skill (e.g., using public transport or cooking) and in the longer term it was a general desire for them to become "more independent". "Living in own home independently" was not stated as a priority for parents of adults on the autism spectrum in the short term (1%) or long term (1%).

Emotional wellbeing was seen as more of a longer term priority (26%) than a short term priority (14%). In the short term "to be happy" was identified by 5% of parents and 14% in the long-term. Priorities in the short term for parents were to increase their child's confidence and self esteem (see Table 2 in Appendix 3).

For further detail on parent's response pattern to these questions please see Appendix 3.

4.2.5 Focus groups with parents of young people on the autism spectrum

Focus groups were held with 35 parents whose children were receiving their education in a range of settings (specialist pre-school; specialist primary school; secondary ARB; full-time mainstream). Views and opinions did not vary greatly amongst these groups of parents and many of their priorities strongly aligned with the survey data above.

Parents were asked to think about the future for their children. They were asked for both immediate aims (i.e. in the next year) but also long term goals and concerns for their child in adulthood. Parents' views on these topics depended greatly on the current age and abilities of their child. Parents of very young children wanted their child to achieve essential skills (**"I know that I need to have him out of nappies and talking if I want him to join a mainstream provision at 5"**) and were struggling to think about their child's long-term outcomes. Parents of older children also had difficulties to think about their child's adult life outcomes and were rather preoccupied with concerns about the transition from school into further/higher education or working life:

"In terms of what my son's going to be when he leaves school and what he's going to do...I couldn't really answer that to be honest with you I can't see myself 3 months down the line"

Most parents said they would strive for independence for their child: **"That they can go to the shops, come back safely; Learning how to put money in a bank and things like that."**

Others stated that their ultimate aim was for their child to get a job: **"Education is redundant unless it leads you somewhere".**

Some suggested that their children would make very good employees: **"They won't have a Monday blue as they don't know what a Monday blue is...they'll always be reliable."**

Many parents recognised that their child may do well academically but may not cope independently or socially in adult life.

Some parents considered it important to resolve issues such as difficult, inappropriate or embarrassing behaviour so that their child's future was not affected in terms of how others responded to them:

"My child is six and half. When he does something people look at him with more understanding, more kindness because he is a small child. But I have seen older children do something and the attitude of people is very different, it's 'very bad'."

Several parents thought it important that their child develop an understanding of their diagnosis and be proud of their identity.

"To be in a position where he understands that he's autistic and that with autism there comes difficulties that he'd find magnified compared to other children....and then sort of learn how to manage them and to cope with them.... and maybe use it to his advantage."

Almost all parents mentioned their concerns about a future when they were no longer around to support their child with autism:

"It's absolutely frightening...there is still the apprehension of how they're going to cope independently; When I'm no longer on the planet what is life going to be like for my child, how are they going to cope?"

Some parents talked about the importance of siblings:

"I'd like the siblings to be given lots ... of help, support, because at the end of the day the siblings are going to look after them... not look after them but at least keep their eye on them."

Almost every parent summed up by saying that they'd want their child to be **"happy and healthy, that's all that matters".**

One parent summarised her understanding of good outcomes for children with autism:

"(as a parent) if you're asked what do you want out of life for your child, you want them to be happy and you want them to fulfil their potential, whatever that is. And you want them to have some meaningful and purposeful activity in their adult life, maybe some kind of paid work, maybe not, but also leisure activity and you want them to have meaningful relationships and to enjoy being with other people."

4.2.6 Interviews with academics, commissioners and regulators

Interviews were conducted with 12 service providers, commissioners, regulators and academics to ask their opinion on what constitutes a good adult outcome for someone on the autism spectrum.

A service provider supporting adults into employment felt that attaining the adequate set of skills to be in a job would be most likely to lead to a good outcome. To achieve this she felt that the adult on the autism spectrum should have the ability to get on with others, have good daily living skills, have the capacity to shift jobs and to plan sequentially. She added that:

"The most important thing is to give people a reason to get out of bed in the morning. To have a sense of purpose and I think that is what ultimately brings you happiness.

For the people I work with, sometimes we might not manage to get them into a paid job, but we might get them to believe in themselves and give them some tools to succeed better in life, like knowing who to turn to for support or what to say in an email and how long it might take for someone to respond. And often getting any type of occupation, even voluntary, has a massive impact on what is going on at home. It can change someone's personality, give them the confidence to talk to people, travel alone on the bus."

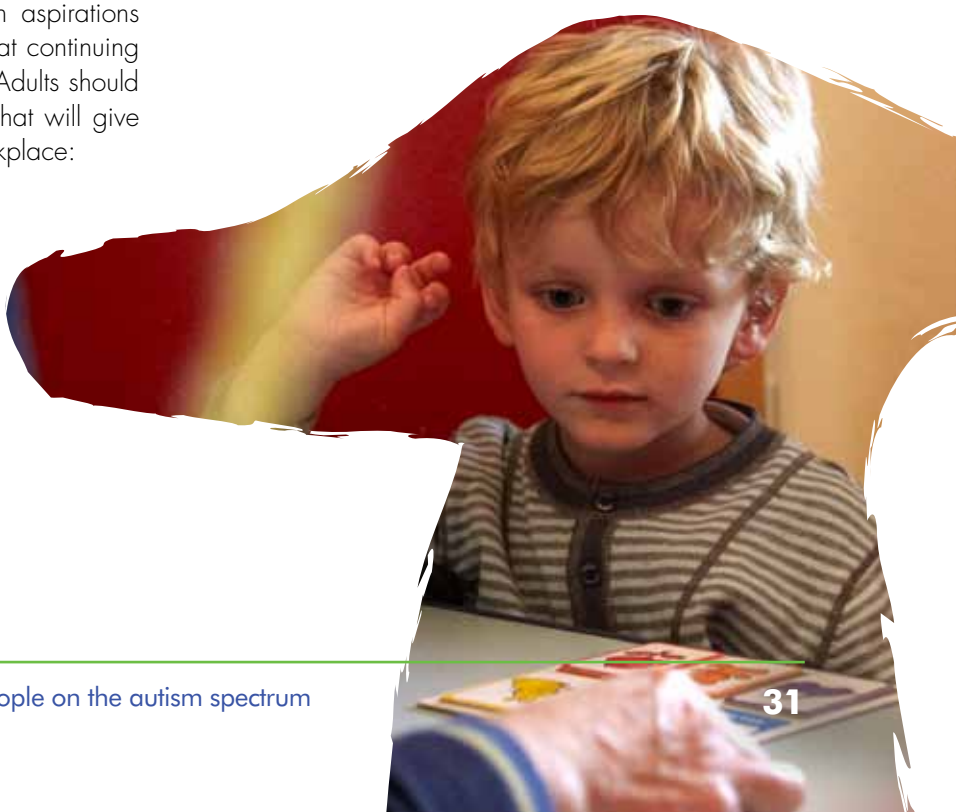
An interviewee who works with disabled students in further and higher education suggested that high aspirations should be set throughout adulthood and that continuing in education should always be an option. Adults should be given the chance to study on courses that will give them real skills that will transfer into the workplace:

"Currently adults with autism may be in further education but they may have seven food hygiene certificates, rather than something meaningful."

Other interviewees commented on the need for high aspirations and the importance of not giving up on academic attainment. One academic noted that it is important to provide young people on the autism spectrum with the opportunity to continue their education until they have achieved their full potential - and that this might often be slightly later than in typically developing peers: **"Not achieving GCSEs at 16 doesn't mean that this is an unreasonable expectation. It might just be an unreasonable expectation at 16 and will be achievable at 18."**

A national educational service provider described good adult outcome for someone with autism very simply:

"Good adult outcome for me would be enabling the person with autism to have the same choice as a person without autism would have."



4.3 Defining good adult outcomes – Summary

A review of the existing literature suggested that there is a lack of a clear definition of what good adult outcomes should be and that what is right for someone without autism may not be the same for someone with autism. Broadly speaking, when different stakeholder groups were consulted about their opinions on defining good outcome there was good consensus as to what they hoped adults with autism could achieve. One clear priority was meaningful employment as a job seemed to provide the person with independence, financial security, the opportunity for social contact and a sense of self-worth. However, employment was not an immediate target for all as they felt they would need to develop other key (academic, personal or social) skills before they were ready for work.

Parents' top priority for their children's adult life was to have good social relationships, although from the survey of adults with autism it was clear that, either by choice or not, many adults were not successfully accessing social networks. A clear short-term priority for parents was for their children to increase their self-confidence and self-esteem, important skills to gain for developing strong social relationships. A number of individuals with autism also mentioned the importance of social relationships, even though many of them did not, or chose not to, have social contact.

Independent living was another priority but clearly there was an emotional bond between families that made this more of a challenge. Children with autism reported that they would miss their parents when they leave home, and parents themselves reported that their child living independently was not a major priority. Some parents and practitioners reported that key academic skills, such as learning to read and write, were seen as important good outcomes for some adults with autism. Many individuals on the autism spectrum reported that a good adult outcome would be for them to have good mental health (e.g., to be less anxious or depressed) and many respondents commented on the importance of feeling happy.

5. Educational planning for good adult outcomes

5.1 Literature review

5.1.1 Policy and Practice

Government advice on educational planning and setting developmental targets is aimed at all pupils with special educational needs rather than specifically at children and young people on the autism spectrum. The term 'special educational needs' (SEN) has a legal definition, referring to children who have learning difficulties or disabilities that make it harder for them to learn or access education than most of their peers (See Directgov website). Where a child has special educational needs, a school has statutory duties under the 1996 Education Act.

The SEN Code of Practice states that there is a continuum of SEN and that, where necessary, increasingly specialist expertise should be used to address a child's needs. Thus there should be a graduated approach to addressing children's SEN (summary of schools statutory responsibilities under SEN legislation, 2011) – following a 'wave of intervention' model. Wave 1 is about what should be on offer for all children: the effective inclusion of all children in high-quality everyday personalised teaching. Wave 2 describes targeted small-group intervention for children who can be expected to catch up with their peers. Examples are the literacy programmes Early Literacy Support (ELS), Year 3 intervention and Further Literacy Support (FLS). Wave 3 is about intervention for children for whom Quality First Teaching and Wave 2 catch-up programmes are not enough ('Leading on Intervention: Strengthening the quality of everyday inclusive teaching', DCSF). Children receiving Wave 3 support will be placed on School Action.

School Action may consist of:

- different learning materials;
- special equipment;
- group or individual support;
- more adult time for planning help and monitoring effectiveness;
- training for staff to enable them to help the child more effectively.

The *'Progression 2010–11 Advice'* focuses on maximising the progress of learners with SEN (DfE, 2010) by using attainment and progress data where learners are working below expected levels. Its aim is to provide advice to teachers, school management teams, school governors, Local Authority officers, Ofsted inspectors and parents for all learners who are performing below age-related expectations. It allows the collection of data sets to encourage tracking and the evaluation of progress by introducing benchmarks against which the achievement of individuals and groups can be compared, and offers schools a framework to judge the proposed target goals.

An Individual Education Plan (IEP) is a document for schools to record short-term targets and strategies for an individual pupil and should only record that which is additional to, or different from, the differentiated curriculum plan that is in place as part of normal provision. The Code of Practice on the Identification and Assessment of SEN (DfE, 1994) *'favours IEPs for furthering the education of children with SEN'* (Godard, 1997, p.172). Strategies used to enable the pupil to progress at School Action or School Action Plus should be recorded in an IEP.

An IEP should contain:

- short term targets for the individual;
- teaching strategies to be used;
- provision to be put in place;
- when the plan is to be reviewed;
- success and/or exit criteria;
- outcomes (CoP, 2001, p.54).

According to Ofsted (1999) the IEP is seen as a tool to help plan for and teach the pupil. It is recommended that the IEP should be reviewed at least three times a year and parents should be consulted as part of the review process. Additionally, the SEN Code of Practice, 2001 states that practitioners should ensure that the young person is involved at an appropriate level. Arrangements for writing IEPs should be planned and agreed with all the staff, and endorsed by senior management. The National Autistic Society's guidance pages on IEPs suggest that teachers should consider the following:

NAS guidance on IEP:

- the individual's progress;
- parental views;
- the pupil's views of their own progress;
- how effective the IEP has been;
- anything that is affecting progress;
- any updated information and advice;
- future action, including changes to targets or strategies.

They go on to state that all staff in schools or educational settings, and not just SENCos, who may come into contact with the pupil should be aware of the targets and strategies in their IEP.

Despite advice in the SEN Code which strongly recommends them, IEPs are not used universally. Most schools however, according to Ofsted (1999), do use them and believe that IEPs are good practice. Nevertheless, for schools that choose not to use IEPs, they have to demonstrate that they are using an alternative which is at least as effective. Provision mapping (DfES 2005) is a way that a school can present a straightforward visualisation of the range of provision on offer for children with SEN. Provision Mapping can work alongside IEPs and provide schools with a way of identifying where there are gaps in their provision and where there are associations between pupil progress and specific aspects of provision.

Despite official government guidance only focussing generically on SEN, there are a couple of supplementary good practice guidance documents available for practitioners working with young people with autism. The first is a joint Department for Education and Department of Health Autism Working Group document: 'Autistic Spectrum Disorders Good Practice Guidance' 2002 (part 1). The document states that:

"Staff within all types of school and early education settings where children with an ASD are educated will need to understand the implications of ASDs for teaching and learning and should look to modify the environment and how the curriculum is planned and taught to enable the placement to succeed. There are aspects of pre-school, school education and the curriculum which require special attention, whatever the type of educational placement and whatever the nature of a child's difficulties." (p.15)

Another autism specific training resource (online and DVD) is the DCSF (2009) *'Inclusion Development Programme Guidance for practitioners in the Early Years Foundation Stage'*. This resource is relevant to all practitioners, teachers, managers and leaders working within the EYFS, with children from birth to the age of five years. While advice does not differ from the generic advice in the EYFS document, it does offer specific direction for staff working with children with autism to help them develop an inclusive environment for children to learn and an appropriate curriculum for them to succeed. This includes the following six areas that staff should give attention to:

Personal, social and emotional development: Children with autism will need additional support to develop understanding of the needs, views and feelings of others and to form good relationships with adults and make friends with peers.

Communication, language and literacy: Children with autism will need help to interact effectively with others, to take turns in conversation, to understand jokes and idioms.

Problem solving, reasoning and numeracy: Basic numeracy can be a relative area of strength for some children with autism as numbers are ordered, predictable and the way in which they are used in calculations follows consistent logical rules. Problem solving and reasoning can be more of a challenge for the child, given difficulties in flexible thinking, social understanding and verbal reasoning.

Knowledge and understanding of the world: Children with autism will need support to help them to make sense of the world, particularly the social world. They may need encouragement to investigate new objects and materials and to use all their senses effectively. They are likely to have difficulty generalising knowledge and concepts from one context to another.

Physical development: Children with autism may need encouragement to try out new things, as they may have developed strongly preferred physical activities which they feel secure with and choose to repeat. Although some children with autism can be very agile, others may have reduced awareness of their own bodies, leading to difficulties with navigating obstacles and with fine motor tasks such as fastening buttons or zips.

Creative development: For some children with autism, art or music may be relative strengths. However, it is a myth that lots of children with autism are highly gifted in these areas (DCSF, 2009, p.7).

Finally there is the 'Primary and Secondary Inclusion Development Programme (online and DVD) – *'Supporting pupils on the autism spectrum'* for teaching staff in mainstream primary and secondary schools (DfE, 2009). One of the key aims of this training resource is to improve outcomes for pupils on the autism spectrum.

'Supporting pupils on the autism spectrum' (IDP)

- What is the autism spectrum
- Social and emotional understanding
- Communication and language
- Flexibility of thought and behaviour
- Sensory perception and responses
- Know the pupil
- Curriculum priorities and inclusive practice
- Sources of support

While these documents and resources are useful and demonstrate positive intentions to improve access to education for individuals on the autism spectrum and provide guidance for teaching staff, they generally possess a lack of longer-term planning towards adulthood. Indeed, it is often unclear whether long-term planning in educational policy is even a consideration. There is also little evidence about whether informed educational practice has a long-term vision towards achieving positive adult outcomes. As Wilkinson (2010) comments, with *'higher school exclusion rates and greater gaps in attainment for ASD pupils compared with their typically-developing peers…there is a need for improvements in educational provisions for these pupils'* (p.15).

5.1.2. Research literature on planning for good outcomes

There is little evidence in the research literature of studies specifically setting out to investigate strategies for achieving good adult outcomes when working with young children. Rather, studies reflect the priority of compensating for the difficulties that arise from autism and to find ways of reducing those problems (Jones et al., 2008). By focusing on overcoming certain aspects of the child's difficulties, it is therefore hoped to equip the child to cope better, and one would hope that this would then contribute to better outcomes in adult life. There is also recognition that interventions need to take into account a number of factors, including the child's characteristics, parental preference, staff expertise and the goals selected (Jones et al., 2008; Parsons et al., 2009; 2011).

So what evidence exists in research studies that may be relevant to current practice in educational outputs and planning? The studies reviewed below used a range of assessment measures, different aspects of functioning were measured, and the length of studies varied drastically. Although the research literature clearly highlighted the heterogeneity of the evidence base underlying interventions, different treatment intensity, study settings, sample characteristics and outcomes, there was also striking consensus about the areas of development which were focused upon in the studies. Academic attainment did not feature as a general focus in these studies as there were very few empirical studies evaluating interventions to improve the academic functioning of young people with autism, with only two studies focusing specifically on cognitive or intellectual functioning (Roberts & Joiner, 2007; Bell & Kirby, 2002). In fact, all the remaining studies reviewed could be grouped into those that addressed wider aspects of development and looked at comprehensive programmes, assessing a wide range of developmental domains, including IQ, adaptive behaviour, language, social competence, school placement and family factors. The remaining studies primarily focused on social interaction and social communication.

Multi component intervention and comparison studies addressed critical developmental domains and examined effects of interventions for a *wide range of outcomes* across a range of developmental areas, skills and behaviours. These studies measured outcomes as a result of either multi component interventions or specific interventions, or they compared different interventions to one another in relation to a range of developmental domains. They had a wide focus in terms of the areas of development they addressed and they incorporated a range of teaching techniques, targeting different skills, across different contexts (e.g., home and school). The premise of such programmes tended to be that outcomes for children can be enhanced through the use of several techniques that can be adapted to the individual needs of the child, and used flexibly according to naturally occurring opportunities for learning.

The literature review revealed that a large proportion of the studies focused on social interaction and social skills training. With preschool children, many of these studies focused upon teaching children play behaviours.

Several studies focused on teaching strategies that aimed to enable the child on the spectrum to improve peer interaction and peer relationships, including strategies to teach the child how to play with other children (e.g., Johnston et al, 2003, Broderick et al, 2002, Garfinkle & Schwartz, 2002). Other studies evaluated specific interventions that included helping the child how to deal with social situations by learning skills related to social greeting and sharing with others (Simpson et al, 2004) or by focusing on teaching children to respond in emotionally appropriate ways (Gena et al, 2005).

A number of studies focused specifically on the methods and tools used to enhance peer interaction with some of these studies focussing specifically on supporting children on the autism spectrum to interact with other peers with a range of special educational needs or they focused upon improving the behaviour of the child on the autism spectrum and teaching social behaviour.

Furthermore, a number of studies focused on social communication, and these studies can be conceptualised as falling into the areas of functional communication, joint attention, specific language skills and the Picture Exchange Communication System (PECS, Bondy and Frost, 1994). Some studies looked in general at functional communication and social communication skills with a number of studies examining joint attention. There were also a few studies measuring children's progress in specific language skills including two studies that looked at precursor skills for understanding pictures or symbols, both covering preschool. Furthermore, Cihak (2007) explored whether nonverbal children with autism could acquire picture-reading skills and, therefore, develop visual literacy. Yoder and Stone (2006) compared the effectiveness of the Picture Exchange Communication System for facilitating intentional communication with Responsive Education and Prelinguistic Milieu Teaching

(RPMT), whilst Howlin et al. (2007) conducted a randomised controlled trial (RCT) on the use of PECS to see whether PECS would lead to increases in spontaneous communication.

In summary, our review found that the research literature has prioritised outcomes related to functional goals, with the emphasis on skills that allow the person to interact with many people and participate in a wide range of activities. This aligns with the notion that *"the ultimate aim of all intervention is increasing competence in natural settings associated with the child's life"* (New Zealand Autism Spectrum Disorder Guideline 2008, p.99). This shows the need to take into account emotional, social and behavioural measures as well as attainment when examining the question of educational impact or progress for children with a range of special educational needs and disabilities. Furthermore, intervention programmes for children on the autism spectrum are likely to be most effective when they begin before the child is five years old, capitalising on the plasticity of the developing brain, and should include natural language learning settings, and actively involve the family (see also National Research Council, 2001).

5.2 Consultation data analysis

5.2.1 Adult survey

Perhaps unsurprisingly, given that the majority of the 69 survey respondents were diagnosed with Asperger syndrome in adulthood, most had attended mainstream primary (67%) and secondary (69%) schools without any specialist provision (a unit or base) for children and young people on the autism spectrum. A minority of individuals attended such units during primary (3%) and secondary (9%) years; and a small number attended other types of provision.

Respondents were, on average, less satisfied with their experiences at school and how well school prepared them for adult life (this means that they responded on a 5-point Likert scale 'I don't think so' or 'definitely not' to the questions below). When asked to rate their experience at school, 58% of respondents indicated that they had not achieved the qualifications they wanted at school; and 48% felt they had not had the same choices as other people when they left school. 61% of respondents were dissatisfied with the information they had been given at school to enable them to decide what to do next and 52% responded that they did not feel they had a number of options to choose from when they left school.

Adult respondents were asked to write-in their responses to the *most* and *least useful* aspects of school that had prepared them for adult life. There were 48 written-in comments about what was *most* useful at school and these fell into six main categories (3 responses were excluded because they were unclear)

"The MOST useful thing that I did or learned at school/college that has helped me as an adult is:"

1. General or specific academic skills (13 comments) e.g., *'Academic learning which enabled me to continue studying at a higher level in middle age'; 'academic qualifications'*
2. Social, communication and life skills (10 comments) e.g., *'life and about me as a person'.*
3. Miscellaneous other than school (9 comments) e.g., *'I wouldn't say the things I learnt at school have helped me on my journey to adulthood'.*
4. The impact of the hurtful attitudes of other people (5 comments) e.g., *'The discriminatory nature of society! How to survive being bullied'.*
5. Environmental support (type of provision; involvement of staff; 4 comments) e.g., *'I had very useful support assistants at school who helped me structure and manage the work that I did'.*
6. School was a struggle (4 comments) e.g., : *'I struggled throughout secondary school and as a result I was suspended three times. Mum asked if the school could refer me to a child psychologist but the school refused. Aged 24 I was diagnosed with ADHD and at 26 with Asperger's syndrome. I was failed by the system and as a result the most useful thing I learnt from school is to try and make people aware of the consequences of children being undiagnosed!'*

There were 46 comments about what was *least* useful at school and these mostly represented 3 main categories (7 comments were not included in these categories either because they did not add very much in terms of detail: e.g., *'nothing', 'not sure', 'everything'*. In addition, two responses were categorised into more than one category because respondents commented about different things):

"The LEAST useful thing that I did or learned at school/college that has not been helpful to me as an adult is:"

1. Specific aspects of or topics within the curriculum (10 comments): e.g., *'A Level General Studies which was compulsory – absolutely useless'; 'Mathematics; just couldn't understand algebra etc and was asked to leave GCE O Level class*
2. Social and communication difficulties / social skills, and bullying (10 comments): e.g., *'Forced Social Interaction i.e. Wasn't at the right social developed level'; 'being bullied. It was severe enough to have a lasting effect even 20 years later'; 'life skills should be taught more e.g., first aid, green cross code, social skills!'*
3. Lack of support / inappropriate support (not fitting in) (11 comments) e.g., *'Being forced to be able to explain why a correct answer was correct. As an adult if I try to think too deeply about why I'm carrying out any action I become immobile'; 'I had an obvious memory problem the school never thought to check into leading up to a nervous breakdown at 17 which trashed 3 A levels. The school wondered about that but were ineffective with response. My entire life profile was changed for the worse.'*

5.2.2 Focus groups and interviews with adults on the autism spectrum

Focus groups and interviews were held with adults on the autism spectrum to gather more detailed information about their time at school, what support they had, and what helped/hindered them at school. They were also asked what they felt best prepared them for adult life.

Many of the focus group members who attended mainstream school talked about the debilitating effects of being bullied, particularly during break time:

"In the playground I used to stand and face the wall. I felt like a misfit. I didn't understand what was going on around me. When you are different that is when you get hit."

"Although I had my diagnosis I didn't feel the teachers were sympathetic to me. They didn't do anything to make it easier. I was bullied really badly. Teachers even saw it and didn't do anything. Eventually I blew up and trashed the classroom and had a nervous breakdown."

These personal accounts of bullying had clear long-term effects into adulthood. The emotional damage of bullying and social isolation affected their academic achievement, mental health, self-esteem and outcomes in adult life. One adult said that it would have been useful to have an "emergency contact" at school which was a person who understood about autism and could help him when things went wrong. He said that it is not always easy to talk to a teacher or the school nurse as young people might fear that what they say could affect their grades.

Several adults suggested how useful it would have been to have a **"safe haven"** within the school, a place where they would have been safe from bullies and could take part in activities (e.g., chess club) or just read quietly to 'recharge their batteries' instead of being in difficulties during unstructured lunch and break times.

Some of the participants, who were currently living in a residential home, remarked that looking back it would have been important to have learnt more basic skills in reading, writing and maths. One man remarked that being able to count properly would make it much easier to buy things in shops.

When asked about their likes and dislikes at school, there was a strong sense that many were helped by being given structure and clear instructions:

"I liked the structure at school. I used to be organised at school and now I'm disastrous. At school you were told what to do, which made it easy."

"When I did my GCSE a lot of the assessment was via coursework and that didn't suit me. I very much liked the structure of exams. With coursework it is just you being left to get on with it and it is not very structured. They just thought I wasn't making an effort and it was really stressing me out. But I just didn't know what to do."

Another focus group member described how sometimes schools seem to see benefits in varying the delivery of course material, something that he really struggled adjusting to:

"In college we had to complete a questionnaire at the end about our experience and one of the questions was 'did your teacher keep things interesting for you by varying the methods of teaching? Agree or disagree'. And I didn't know how to answer; I don't like when things vary. I wish others liked it my way. At school they assume that everyone likes variation and new things."

Another man with Asperger syndrome said that it would have been helpful to have worked more on study skills at school, such as being given advice on how to prepare for exams at school (e.g., how to set out the work, what is the reason for completing these questions, length of time to spend on each, etc.).

One member of a focus group highlighted some of the difficulties adjusting to the way children and young people are typically taught in school. The example he gave was of working in groups. Because of his social difficulties he never enjoyed group work and although he had a keen interest in learning a foreign language, he found the group work too much of a challenge and received no extra support. Eventually this negatively impacted on the final GCSE grade he achieved.

When preparing for leaving school some of the focus group participants felt that the careers advisory service could have done more to prepare them for employment and to choose their options:

"I never had any ideas about the future or what I wanted to do when I was older. It was only when I did work experience that I realised what I enjoyed doing. The career advisor at school wasn't good. We were given a tour of the Careers Advice Centre and told here are the leaflets, have a look. It wasn't explained to me what I needed to do to get to a particular job."

5.2.3 Survey of children and young people on the autism spectrum

Data from the children and young person's survey were summarised to look for common themes across respondents. There were 30 respondents to this survey, which is a smaller sample compared to the other surveys. The data are therefore not presented in terms of percentage of respondents to the items but, rather, are summarised below.

The overall pattern of data suggests that participants were more favourable in their responses about their experiences in primary school than in secondary school. Many children made points regarding specific qualities of primary school which are different in secondary provision, with factors being noted such as the small size of the classroom, the structure of the lesson environment and consistency (e.g., **"I stayed with my class all the time and I was used to it"**). One young person even stated that the worst thing about primary school was **"leaving to go to secondary school".**

Like adults with autism, young people also emphasised that in both primary school and secondary school they enjoyed the opportunity to make friends. The opportunity to take part in specific subject areas was also welcomed (**"The best thing about secondary is doing really well in Maths"**), perhaps reflecting the opportunity to learn about a topic where they have a specific interest or skill. It was also notable that Autism Resource Bases were mentioned as a positive feature at secondary school and these seemed very important to the young people who mentioned them: **"Being in an autism base means the teachers understand and it's a safe place".**

Several young people described bullying as the worst thing about both primary and secondary school: **"Kids would try their best to wind me up and provoke a reaction"**. They also commented that they found the behaviour of their peers hard to interpret at secondary school level. Two of the respondents commented that their behaviour may play a role in how successfully they develop social relationships, with one stating that they were: **"bullied in my first schools for not understanding social norms."**

Homework and time management was a clear stressor for some young people with autism. One pupil noted that the worst thing about secondary school was: **"The assumption that I would have independent study skills"**. The quality of teaching was also subject to criticism in both primary and secondary education, although this was a problem area in the view of a minority of young people with autism.

5.2.4 Focus groups with young people on the autism spectrum

Several children and young people had difficulty answering questions about how school could help them achieve their goals and therefore they were not consistently asked such questions. Nevertheless, certain ways in which school could help young people achieve their ambitions were implicit in their responses to related questions during the interview.

There were two main themes. The first of these related to relationships with teachers – particularly mainstream teachers. For many children, liking or disliking a particular subject was largely related to their liking or disliking of the teacher; if their interactions with their teachers were generally positive, then they tended to like the subject. While this preference is probably also the case for the majority of young people without autism, those with autism interviewed for this study expressed more than just a casual preference; their responses reflected a strong desire for teachers to **"understand me"** or **"understand my autism"**. This was indicated by the way that several students talked about their difficulties coping with the demands of upper secondary school:

Student 1: **"I don't do the theory in Food tech[nology] anymore as the teacher talks too fast. He likes to get a move on."**

Student 2: **"That's like the Geography teacher. I'm really slow at writing and he is too fast for me. I have to write at lightning speed."**

These statements are consistent with several anecdotal reports of the world "moving too fast" for people on the spectrum (e.g., Williams, 1992; also see Gepner & Mestre, 2002), and emphasise the need for teachers to make the necessary adjustments to ensure that pupils can keep up with their learning of material in class.

Other children, especially those who had described their autism in negative terms, expressed the need for greater understanding of autism more generally amongst teachers (and peers), as well as the range of potential challenges that people with autism might face.

"People think I use autism as an excuse ... I hate it when people say that." [11-year-old girl in mainstream]

The second major theme was on making sure that the young people received the 'right' amount of assistance. They were generally positive about the amount and type of help that they received from teachers and, in particular, key workers. These staff members were essential to ensuring that pupils were delivered the material at a pace that they could process it, that they understood the material (particularly for subjects like English or poetry and rhetoric, which for some pupils were "completely beyond [them]"), were organised, and generally coped with the social, emotional and academic demands of secondary school.

Two students with autism who were in secondary mainstream provision accepted that such assistance was helpful but also expressed frustration at the extent of assistance they were receiving. Furthermore, they were also unhappy with how their peers might perceive this assistance. They were worried about being 'singled out' in class, which again relates to their issue of coping with their autistic identity.

Student 1: **"I'm having way too much help at the moment."**

Student 2: **"Yes, it's so annoying you get so much help."**

Student 1: **"It's annoying – they are constantly asking 'are you doing this?' ... It'd be better to just help everybody ... I don't like too much attention on me."**

5.2.5 Survey for parents of individuals on the autism spectrum

When asked about communication with teaching staff regarding their child's progress, parents of children and parents of adults (reporting retrospectively) with autism reported slightly different experiences. Where parents of children were mainly positive ('strongly agree' or 'agree' with the statement) about the regularity (65%) and good quality (57%) of information received from teaching staff, parents of adults were more likely to strongly disagree or disagree with the same statement (53%).

Parents of children also felt that they were listened to by staff when talking about short-term targets (56%), compared to only 28% in the group of parents of adults. Seventy percent of parents of adults (reporting with hindsight) strongly disagreed with a statement about the school their child went to working with the child on what they would like to achieve as an adult.

The majority of both parents of children (85%) and parents of adults (67%) felt that it was important to attend annual review meetings if the child/young person had a statement of educational needs, yet parents of children generally rated the review meetings as more informative (63%) than parents of adults (38%).

For further detail on parents' rating of these aspects please refer to Table 4 in Appendix 3.

We also examined, using statistical analyses, whether the type of school/educational provision that the child with autism was (or had been) experiencing was associated with parents' ratings in this section of the survey. To address this issue, we divided the type of educational services into distinct categories.

For parents of children with autism, their child's current educational provision was coded as: (1) not in education/educated at home, (2) mainstream school (including supported and unsupported placements and specialist resource bases), or (3) specialist schools (both for general special learning needs and specialised for autism). For all bar question 8, there were associations between the child's current educational placement (the two groups currently in a school environment only were compared) and parental ratings. Parents of children in special schools rated their experiences significantly more positively when compared parents of children with autism who were in mainstream schools.

For parents of adults, the last educational placement for the adult was categorised into one of three options: (1) Home educated/Other (2) School (primary and secondary), or (3) College. Parents did not differ in the extent to which they rated these placements.

5.2.6 Focus groups and interviews with parents

In the focus groups, parents were primarily asked about the communications they receive from school regarding their child's progress towards educational targets and how much input they have in deciding upon those targets.

Parents were asked if they understood the assessments used to measure their child's progress and whether they felt involved in the process of monitoring the progress of their child. Most parents focused on the frequency of discussions or meetings and the means of sharing information about their child. Parents in a preschool provision and in a special school were very pleased with the amount of information they were given by staff on a regular basis and felt they got **"a lot more than a standard parents' evening"**. Several parents said it was essential to get good information, especially if their child was non-verbal : **"If you've got a non-verbal child, you need to know more on a daily basis exactly what they do".**

All groups identified several formal and less formal means by which information was delivered including a home-school diary describing the child's daily activities and behaviour, brief discussions with school staff at the end of the day, IEP planning or annual review meetings, home visits and in the pre-school provision a 'Learning Journey' journal, which is a compilation of objectives, work and photographs allowing to trace long term progress. This last means of communication was particularly valued by parents as they could borrow the journal during the holidays to share with family and friends. One parent said: **"we can't see in the future, but looking over the past really helps to put things into perspective"**

The home-school diary was also highlighted as important for those parents who live further away from school as they get little face-to-face contact with teachers and so are reliant on this form of communication. One parent from the focus group preferred getting to speak with teachers rather than relying on the written information alone: **"personal contact is way better; I get so much more out of talking directly to his key worker than reading information in the book".**

Parents whose children were either in secondary mainstream or attending the autism resource base within the school had some concerns that generic reports used in the mainstream provision were not specific or focused enough:

"You need to know why they're not reaching that target and what can be done to help them... Telling me that they've got 'red', well... it doesn't mean anything". And "Ok they've reached that target but what did they actually do to get to it?"

Annual review meetings were generally discussed favourably. Some parents whose children attend a special school were pleased to have time to discuss their child in detail and contrasted this with mainstream schools **"I feel like you can come here** [special school] **and talk and stay as long as you like"**. Others highlighted that the timing of the meeting was crucial in order to draw up the IEP: **"It should really be done in the middle of the school year... when they've had the chance to have the children for a few good months and then set the targets".**

All parents valued less formal forms of communication with teaching staff, such as by email and telephone: **"If I'm concerned about something I might just pick up the phone and talk to** [his teacher]**. I'm happy about that".**

Talking about their perception of the role of education, parents felt they were contributing to their child's education because staff in the special schools and unit would ask them *"how would you approach if?"*, reflecting a genuine reciprocity in parent-teacher relationships. They had not found this in mainstream schools:

"In mainstream school there are 30 children, here only 7. The attention is different. You can't compare"

Parents also talked about key workers and outreach provision. There was a mixed view depending on the perceived quality of the staff and the degree to which the child experienced problems outside the school. Whilst some parents were pleased to have support from the school to address problems with sleep or eating behaviours others thought this was not the remit of education staff: **"They aren't there at night when my child isn't sleeping and nor should they be".**

Parents felt that barriers to progress often arose because of difficulties in accessing appropriate education and thereby preparation for adult life. Such provision rested on having a statement of SEN and many parents spoke with anger or distress about the difficulties they had had with this process: **"So many parents have to go to appeal...and only those parents who fight will get them into a special school".**

Many parents talked about fighting and needing to be strong. **"I had to fight to get respite when [child] was little, really fight". And "You can either sit back and wait for the school to do everything, which they'll do as much as they can or you can go out and try and find things out for yourself – it's a choice"**. However, there was strong consensus that this puts **"financial and emotional strain"** on a family.

Parents felt that schools often struggled to recognise the challenges their family were facing and that this was partly because their children **"look normal and have hidden impairments"**. They also had few appropriate role models. One parent pointed out that **"those** [people] **with Asperger's who succeed don't have a label"**. However many parents felt that the public awareness of autism was improved but it often gave a wrong impression:

"It gives people the wrong idea about autistic children. They think it's wonderful. For most kids it's not like that".

They felt that the school should nurture children's talents and look at strengths. A parent of a child who was eventually home-schooled commented that when her son was at school there was a focus on what he finds difficult rather than working on his strengths and building on his interests. In the home environment he can concentrate more and therefore **"at least we have an opportunity to develop his skills in something, if we can focus on the things we know he already likes".**

Parents also wished that teaching staff would further consider the young person's suitability for particular careers (**"help them develop life skills to do jobs"**).

5.2.7 Survey for practitioners

From the 217 analysable responses to this survey, 18% of respondents were teaching assistants; 18% were autism advisors; 16% were teachers; 11% were speech and language therapists; 11% were SENCos; 5% were heads of autism resource bases; 5% were headteachers and 4% assistant headteachers. The remainder were educational psychologists (N=5), inclusion leaders (N=4), home educators (N=3), and nursery nurses (N=2).

Respondents most commonly worked in mainstream primary (19%) and mainstream secondary (12%) schools. The next most common school settings were general special secondary schools (8%), autism resource bases in mainstream primary (8%) and mainstream secondary (8%) schools. After this the most common school settings were: autism specialist secondary school (6%), local authority autism outreach team (6%), mainstream college (6%), autism specialist primary school (4%), general special primary school (3%) and autism specialist school (all ages) (3%). Practitioners who completed the survey worked with young people with autism from 2 to 25 years.

In terms of frequency of target setting, 42 respondents provided information on the survey. Over half (59%) set targets weekly, one-in-six (17%) set targets daily and one quarter (24%) set targets yearly. A summary of the information used to set targets from 217 respondents is shown in Table 2 below. Two thirds of practitioners reported using classroom observations to help set targets and around half reported using formal assessments and consulting with parents and pupils. Around one third (30%) of respondents consulted national or international guidelines when setting targets. Teachers were involved in setting targets approximately half the time (47%), teaching assistants approximately one third of the time (35%). Assessment co-ordinators were involved in setting around one-in-ten (11%) of targets and a combination of staff in one quarter of cases (27%).

The most common methods of recording targets were IEP records (37 responses), in-house data tracking software (13), checklists developed by B squared (12), paper files (10) and LA SEN recording systems (5). From 125 analysable responses, data monitoring records were most commonly updated termly (54%) or monthly (14%). One quarter of respondents said that data recording targets was updated more frequently (weekly 8%, daily 8%, after each session 9%) whereas 8 respondents (6%) said that data monitoring records were updated only on an annual basis.

Table 2. Information sources used to set targets

Source of information	Percentage of respondents (N=217)
Classroom observations	64.5%
Consultation with parents	55.3%
Formal assessments	51.6%
Consultation with pupils	47.0%
National or international guidelines	30.0%

Respondents were also able to write text comments on any topic into an open box on the survey and 64 respondents did so. Their responses were grouped into categories and sub-categories using content analysis. The (sub-)categories as well as examples of written-in comments are shown below:

Category and subcategories	Sample comment
1. Assessment (N=28) 1.1 Best fit for pupils with autism 1.2 Systematic/formal assessments 1.3 Information on assessments available 1.4 Feedback on assessments	"I would like to see it possible that all local authorities accept the spiky profiles ASD students often have in the NC levels as schools are often forced into reporting false data so that it 'fit' the local authority reporting system this of course results in false data that shows that students with ASD have even fits cognitive profiles which all ASD practitioners know is not the case. It doesn't make things easy when we are trying to explain just how different autism is to other special educational needs as the data we are forced to report shows that in fact we are not." [1.1] "I would like to learn or know more about what other assessments are available to support children with ASD as we only seem to use the most common ones and this does not always show progress in other areas which I think is vital." [1.3]
2. Help from service providers (N=8) 2.1 Importance of external help 2.2 Lack of external help offered	"We would appreciate more supportive organisations who would help us with assessment of students with autism" [2.2]
3 Understanding the autism spectrum (N=7)	"It would be useful to have some focus on the child or young person's understanding of their condition and needs as well as their sense of well-being." "Much more autism training is needed in mainstream schools."
4. FE/HE learning (including difficulties in transition) (N=5)	"There still needs to be more done with regards to the transition into further education and employment and better links with support organisations such as NAS Prospects."
5. Feedback (N=3) 5.1 Feedback on assessments 5.2 Frequency of feedback	"It's difficult to answer as assessment to a large extent is continuous and adjustments are made when teaching and responding to the child. Parents are informed in a diary and with local parents during conversation at the start and end of the day." [5.1]
6. School ethos (N=2)	"I see a large number of children who attend a variety of schools. Their progress and success depends on how autism-friendly the individual school is. In the last decade there has developed a much more confident approach in the best schools. Some have a long way to go."
7. Miscellaneous (N=11)	"[…] It is also very important to have these ASD students in the [Autism Resource Base] asap. It becomes much more problematic when a student has a late diagnosis or is given a place in the Resource after Year 7. The ASD students need to understand and appreciate the life-long implications of their diagnosis."

5.2.8 Focus groups and interviews with practitioners

A focus group of practitioners from an autism special school was asked for a description of how they set educational targets for children at their school. They described using IEP targets on a daily basis and defining broader key developmental targets every term for the child to aim towards.

School staff in several focus groups and interviews explained how the overall target is to teach towards the National Curriculum and P Scale descriptors. However, the teacher's own assessment of child progress towards these targets is also included, which allows teaching staff more flexibility in their approach to target setting.

The inclusion of parents in target setting is usually facilitated through a parents' evening held once a year, which allows teachers and parents to discuss the child's overall behaviour and progress. This meeting usually coincides with the annual review of the child's IEP and adjustments to the programme and goals for the future will be discussed. The young person on the autism spectrum will usually be involved in this meeting. If the young person is approaching a transition to a new school, teaching staff will also discuss plans to prepare this transition with the parents and pupil.

One group of teachers discussed the IEP in more detail. They said that it is important to take the time to get to know a pupil better and to have the opportunity to observe his or her skills, interests and difficulties, before beginning to form an idea of what should be included in the IEP. The teachers highlighted the importance of focussing the IEP on important skills that young people with autism might have difficulties with, such as social communication skills. These broad skills should be broken down into small steps which represent the educational targets defined in the IEP. IEPs are generally established annually, but in some early years provisions targets are reviewed on a termly basis instead. IEPs are typically established by teachers, SaLTs, other members of the teaching staff and sometimes by parents. The annual review meeting provides an opportunity for teaching staff and parents to discuss the educational programme and to adjust or add targets.

When asked about targets they were aiming for with the children in their school, one teacher responded: **"to give them as many skills as possible for them to cope with the future"**. Life skills and social skills were seen as priorities to focus on in educational planning. Teachers also felt that authorities and inspectors should realise that autism specialist teachers are the experts and therefore their opinions should be taken further into account when deciding on educational planning and target setting.

An interview with an autism outreach worker focused on the limitations of working towards National Curriculum level descriptors and that teachers often need to be creative in working around these constraints:

"In a special school setting they do give more priority to life skills and can be more flexible with the curriculum. The greater the learning difficulty the more flexible they can be with the learning goals."

When talking about staff involved in educational planning, several focus group members and interview partners spoke about how Learning Support Assistants (LSAs) play a very important role in the education of many children with autism in mainstream settings. One LSA who was interviewed described how every child with SEN at her school has a Student Profile - which includes their various academic attainment levels, any special needs or difficulties - and how it is the LSA who is in charge of updating this Profile. She explained how this allows LSAs to share some of the large amount of information they have about the pupils with other members of staff, despite the fact that they have only limited contact with teachers and the SENCo:

"LSAs have so much knowledge about the children: we know what is going on at home; we organise their homework; write planners; we are there with the students in most lessons. The only way we have to communicate with teachers is via email and that is down to the initiative of the LSA and how much time they will work outside their paid working hours."

Another LSA remarked that she was only paid for the hours she was in the classroom and not during lunch and break times. She explained that this is common for teaching support staff and that it is therefore hard for her to attend important meetings after school (e.g., IEP planning meetings or parent evenings) unless she commits to those without pay.

An interview with a Speech and Language Therapist (SaLT) focused on children educated at home and some of the challenges faced when educating a child with autism in that context. The interviewee argued that generally speaking children who are home educated are set good academic learning targets but that they are often not being supported and assessed in terms of developing

a range of social skills. Independent living skills are also often l targeted in home education programmes.

In terms of the involvement of SaLTs generally, this interviewee cautioned that with the possible introduction of personalised budgets, where parents would be in a position to buy SaLT services, it would be difficult for parents to make a judgement on the quality of the service offered as there are currently no autism qualification standards for SaLTs that parents could refer to. The interviewee recommended that the NAS or the Royal College of SaLTs could publish a list of qualified practitioners working in autism services. Another SaLT commented that at present it would not be possible to provide a list of recommended qualified practitioners as the range and type of training is so varied. She suggested however that parents should ask private practitioners to provide certificates of autism-specific training, for example in the use of the Picture Exchange Communication System.

5.2.9 Interviews with academics, commissioners and decision-makers

A senior academic in the field of special education highlighted the need to begin educational planning for later outcomes early on in the child's schooling:

"I think working on forming realistic aspirations needs to start earlier, as soon as they enter secondary school or even better in primary."

A commissioner of education supported this notion of questioning; what we are preparing children on the autism spectrum for and how important the child's voice is in this process:

"The Educational Statement is not enough. It is good when the young person is able to say what they want out of their education: to choose where they live; to have meaningful employment; to choose who they live with. These are the sort of things that relate to meaningful choices. Are we preparing our young people to make those?"

One key aspect that was highlighted by the same interviewee was that more needs to be done to promote independence in children with autism. An example was given of individual support in mainstream settings and that staff are not thinking **"where and when does the pupil really needs this support and are there occasions when the pupil can do things without the TA"** [teaching assistant]. She goes on to say: **"Allow them to make some mistakes, so they can learn why they make mistakes and pick themselves up. So by the time they leave school they can make their own choices and aren't so dependent on having an adult next to them."**

An important point raised by many interviewees was that teaching staff needs to receive better training, and that this should include the senior management team. There have been recent improvements in training (for example the use of the DCSF's Inclusion Development Programme) but a future target group for training and awareness raising should be heads of mainstream schools. **"We are now in a situation where teachers and teaching assistants often know more about autism than the head. But it's the head who is taking decisions about provision for pupils with autism, so that can be a problem"** said an educational service provider working across a range of schools.

Another suggestion for development made by several interviewees was that each school should have a member of staff who can act as an "autism expert" to staff as well as students on questions about autism. It was suggested that this autism expert could play an important consultation role if children with autism are being considered for exclusion. The need for schools to have better protocols in place to avoid exclusion of pupils with autism was noted especially as young people who are excluded from school have much poorer outcomes in adult life. Much of one interviewee's legal work is taken up with cases where a child has been permanently excluded from school. He explains how this process can have a dramatic impact on the young person with autism and their family:

"We know that children with SEN and many with autism are eight times more likely to be permanently excluded. SEN are at the heart of most school exclusion cases. In terms of outcomes, being permanently excluded from school is one of the main drivers of poor outcomes for any child. If you've been excluded twice it massively impacts on your ability to go back into mainstream and families often have to rearrange their life to home educate their child. School is

often the most important form of respite for parents. So having a child excluded can be a complete disaster for a family. Mainstream schools are entitled to refuse a child who has been excluded twice and that often happens. And then parents have to travel the country trying to find a school."

This expert further explained that although the permanent exclusion of a child with SEN should only be considered in the most exceptional circumstances, some schools are using this process to get the LA to engage and take their SEN responsibility seriously. He warns that this is an inappropriate and far too disruptive way of dealing with a child's difficult behaviour and that there are much more effective ways of getting the LA involved, such as requesting an emergency annual review or a new statement.

Statutory guidance exists to support children with SEN and their families, including the cases of children who are being excluded from school. However, this legislation is often poorly applied. A representative of an English Local Authority argued that the main reason children with autism are excluded from school is that the school is inflexible and not trying to understand the perspective of the child. The interviewee said that the emphasis should be on the school to relieve the pressure put on children so they would be less likely to be excluded:

"What we try to aim for is that the child is not walking around with a big bag of strategies on his back but rather enable the members of staff overall to have strategies to ease the burden on the child. Staff quickly realise it is not rocket science and by implementing simple strategies it can make a big difference. If you can avoid all the paperwork around exclusion it is well worth it."

Another challenge that was frequently mentioned in relation to educational planning for good outcomes was on how to promote peer awareness and prevent bullying. One suggestion was that if young people with autism were encouraged to find out more about their diagnosis in mainstream schools that it may be possible to educate other young people to act as supportive peers: **"self awareness is very crucial...The more we can encourage people to say 'I have autism, this is difficult for me', the better".**

Finally, transition planning was commented on in many interviews. The consensus was that there currently isn't enough forward planning and the planning is often uncoordinated across the different schools and services. There are a number of good programmes existing to assist in the transition of children with SEN but there needs to be an investment in the training of how to use these strategies and services. One specific area that has been clearly identified as needing further time commitment is in transitioning children out of school/college/FE and into the workplace and planning for this transition should include work placements. One interviewee summarised:

"If children with autism don't go on work placement they have missed out on a very important opportunity. It just seems too difficult for staff. The protective factors that they would need to successfully go on work placement do require a lot of effort compared to other students because you have to work with both the employer and the student."

5.3 Educational planning for good adult outcomes – Summary

Despite the goal of education being to provide young people with the skills to achieve their desired outcomes for adult life, there is evidence to suggest that long-term educational planning does not consistently keep this goal in mind. There was a lack of policy documentation or practitioner guidance that directed teaching staff towards educational planning for good adult outcomes. Practitioners sometimes felt constrained rather than helped by the National Curriculum in their educational target setting and planning, and called for there to be greater flexibility in terms of what curriculum topics they can include for pupils with autism. A range of skills was identified as being important for young people with autism to learn more about at school in order to manage adult life (e.g., key academic skills; social skills; daily living skills; managing the workplace). Indeed, many adults with autism reported leaving school unprepared and unskilled to meet what is required of them as adults.

Improved communication was identified as a key component of successful educational planning. In particular there was a strong preference from parents for them to be more involved in decisions made about their child's education. Parents reported finding it difficult thinking about their child's adult outcomes as they are dealing with the challenges of the "here and now", which further highlighted the importance of sensitively including parents in their child's educational planning.

There was also a call from young people with autism for teaching staff to be more considerate of their preferences and needs when delivering educational content. Within the school itself communication amongst teaching staff could be improved and some highlighted the importance of including in educational planning those staff members who know or spend most time with the child.

Children, young people and adults with autism all voiced opinions on the detrimental effects of being bullied at school (particularly for those individuals who attended mainstream schools). Some suggested that the effects of bullying and social isolation had long-term negative effects in terms of their social and emotional well being, as well as their self-esteem. Improved teacher knowledge and awareness of bullying were seen as key for future improvements, as was providing a "safe haven" within the school, away from bullies. Another key target for the future was to avoid at all costs children and young people with autism being permanently excluded from school as it has been shown to dramatically affect the young person's long-term outcomes as well as the wellbeing of their family.

6 Assessment measures and how they relate to adult outcomes

6.1 Literature review

In terms of measuring academic progress, the P scales are a set of descriptions for recording the achievement of young people with special educational needs (SEN) who are working towards the first level of the National Curriculum (Level 1). The use of P scales is statutory for children with Special Educational Needs, aged 5-16 years who are working below Level 1 of the National Curriculum and since September 2007, the collection of P scale data has been mandatory. The P scales are split into eight different levels with P1 being the lowest and P8 the highest. Level P8 leads into National Curriculum Level 1. Levels P1 to P3 are not subject-specific, as they describe early learning and conceptual development.

According to the DfE's *Children with Special Educational Needs 2010* analysis

"The performance descriptions for P1 to P3 are common across all subjects. They outline the types and range of general performance that pupils with learning difficulties who are not working at levels P4–P8 might characteristically demonstrate. If a pupil is at P1i to P3ii level in English, then reading, writing, speaking or listening levels would not normally be appropriate. If a pupil is at an English level higher than P3ii, then the relevant separate levels P4–P8 in reading, writing, speaking or listening are appropriate and an English level is not expected. The position is similar in respect for mathematics (where levels P1 to P3 are not reported for number, using and applying mathematics, and shape, space and measures). For science, a single level from P1i to P8 is appropriate. However, there may be exceptional circumstances where a pupil is judged to be at P1i to P3ii in English and/or mathematics but at P4 to P8 in a particular element of the subject. Schools' Management Information Systems will allow these levels to be recorded and will transfer all levels as entered for pupils (p.140).

The *Progression 2010-11: Advice on improving data to raise attainment and maximise the progress of learners with SEN* includes a point score system to allow schools to distinguish attainment within the P levels using a nationally agreed numerical value. The document states that there are three principles that underpin the advice given.

1. High expectations are key to securing good progress.
2. Accurate assessment is essential to securing and measuring pupil progress.
3. Age and prior attainment are the starting points for developing expectations of pupil progress.

The Assessment for Learning strategy (DCSF, 2008) aims to support schools in developing their assessment of pupils to enhance learning and improve the rate at which pupils progress. According to Wilkinson and Twist (2010) the *'intention is that collecting information about pupils' ongoing performance will enable teachers to adjust teaching to meet pupils' needs more effectively'* (p.7). However, it has been noted that many of the official guidelines provide little or no precise advice about using this approach with young people on the autism spectrum.

6.2 Consultation data analysis

6.2.1 Practitioner Survey

The frequency of use of the most common assessment measures is shown in Table 3 below. P scale and NC levels were reported to be used by over three-quarters (76%) of respondents. In addition, over one third of respondents reported using measures that are more autism-specific, such as establishing children's sensory profile (41%) and their use of PECS (39%). B squared (29%) and PIVATS (21%) were used by more than one-in-five of respondents and CASPA (13%) was used by more than one-in-ten to record pupil's progression in relation to NC and P Scale levels. Respondents were asked to indicate what other formal and informal assessments they used. The responses indicated that a number of 'bespoke' systems were in place in many schools, and also a range of standard clinical assessments were used focusing on language and communication abilities (e.g., Clinical Evaluation of Language Fundamentals CELF), measures of autism (e.g., Autism Diagnostic Observation Scale ADOS) as well as measures of general ability and reading and writing attainments – although most additional measures were mentioned by less than a handful of respondents.

Practitioners were asked to indicate which assessment tools were most useful for measuring the progress of young people with autism in a number of domains. The most commonly cited tools are summarised against the domains of progress/functioning in Table 3.

Table 3. Assessment tools used by schools to assess specific domains

Domain of progress/functioning	Most commonly cited assessment tools (Number of respondents)
Language (non-verbal children)	PECS (14) Working with SaLT (7) P Scales/PIVATS (7) SCERTS (6) B squared (6) ABLLS (4)
Language (verbal children)	P Scales/PIVATS (9) CELF (9) Working with SaLT (8) SCERTS (5) B squared (5)
Independence	P Scales/PIVATS (9) B squared (7) PECS levels (6) Learning skills profile/IEP (5) PEP-R-III (4)
Social	P Scales/PIVATS (12) Checklists from A. Kelly's Talkabout books (7) B squared (6) SCERTS (4)
Managing stress and behaviour	Informal observation/tracking (11) Visual 'Anger scale 1-5' (5) SCERTS (4)
Managing sensory issues	Sensory profile, some named the profile included in the IDP material (17) Informal observations (5)
Planning adult outcome	SCERTS (5) P levels/PIVATS (4) B squared (3) General transition planning (3)

As would be expected given the range of practitioners who responded to the survey, the wide range of pupils they worked with, and the breadth of progress/outcomes enquired about, a range of instruments were considered 'best measures' of the various domains. Some instruments were seen as useful for measuring a wide range of outcomes, notably the generic measures for P Scales: PIVATS and B squared. However, other more autism specific assessments were seen as useful for measuring progress, including the PECS assessment (to assess communication in non-verbal children; independence), the SCERTS ® assessment process (to assess communication in verbal children; social progress; managing stress and behaviour; planning for adult outcomes); the CELF for language and communication in verbal children; the Psychoeducational Profile (PEP) for progress towards independence; the checklists included in A. Kelly's *Talkabout* books to measure social progress; visual 'Anger 1-5' scales representing different levels of anger or other emotions, helping the person to manage stress and behaviour; and measuring sensory issues using a sensory profile.

The final part of the survey asked practitioners about feedback of assessment data and progress reports to parents. From 121 respondents who indicated a specific frequency of feedback to parents, 45% reported feeding back termly and 35% reported feeding back at an annual review. A lower proportion of respondents reported feeding back more frequently: monthly (6%), weekly (2%) and after each session (4%), the later largely being SaLTs. Nine respondents (7%) reported that outcomes of assessments were not routinely fed back to parents. In terms of the quality of the information fed back to parents, practitioners made a rating on a 5-point Likert scale to the statement 'Your school/college provides parents of pupils on the autism spectrum with *good quality* information' (where 1 is 'strongly agree' and 5 is 'strongly disagree'). The mean response was 2.2, indicating that most practitioners felt that the information was of good quality. Responses at the top and bottom of the scale indicated that many more practitioners 'strongly agreed' that the information was of good quality (N=29) than 'strongly disagreed' (N=2).

Health practitioner input

Practitioners recognised that pupils on the autism spectrum had high needs for expert help, in particular from health practitioners including SaLTs and OTs. Where this help was forthcoming school practitioners could see its value and positive impact.

"Issues concerning concentration and sensory seeking behaviours need more than a behavioural approach ('top down') and should be referred to a specially trained Occupational Therapy team for assessment to work on a 'bottom up' approach to build a child's core skills."

However, several respondents found that little or no access to such expertise was available locally.

"As a school we do our best but often find there is little outside support for advice. The [local] CAT team is fabulous but we struggle for support from OTs and speech and language team".

Information on assessments available

Many respondents wanted to hear and learn more about assessment tools that other schools found useful.

"I would be very keen to have some feedback about assessment tools that other schools and colleges use that they find useful."

They were keen to use assessments more relevant to some of the challenges faced by pupils with autism but did not know which tools to use.

"I would love to use a systematic assessment system to measure non-academic progress. What? How? Give me advice and I will take it"

Several practitioners expressed the view that NC and P Scales did not capture the set of skills and learning that pupils with autism require or take account of their 'spiky profile' across attainment areas.

"The National Curriculum clearly does not fit the needs of many children with ASD. It is very frustrating to try and assess their progress using the National Curriculum and P levels when many of the children have other more important skills they need to learn before they can access the curriculum and this progress is then not shown on CASPA as it only considers academic progress which for many is not going to be huge. It also does not take into consideration that children with ASD sometimes learn something in one situation but are then unable to apply this or repeat this if something changes such as the person they are working with or the room or the colour of the equipment etc."

6.2.2 Focus groups and interviews with practitioners

Practitioners were asked via focus groups and interviews about the range of assessments they use when children with autism enter their school and how this informs the future educational planning. Opinions were also gathered on whether these measures are assessing skills related to good adult outcome.

The protocol used in a special school for children with autism means they first assess children's knowledge of English, Maths and Science. This allows the teachers to group the children in terms of general ability level, but this information is then not used to track progress over time.

A group of practitioners at a nursery for younger children with autism often make a home visit where they assess the child's current level of social communication. They also complete a questionnaire with the parent on: toileting; sleeping; eating; problem behaviour; general social impression; ability to imitate; following instructions; turn taking and sharing play; speech and communication; problem solving strategies; symbolic play; hand eye coordination; whole body movement. In addition, the nursery's Occupational Therapists completes a sensory profile for the child and assesses fine and gross motor control. The period of assessment data collection is quite intense early on and the data are used to guide the content of the IEP.

One group of practitioners used video and photo material of children to collect evidence of changes in the child once they have established the IEP targets. This visual evidence of progress, in addition to all the other baseline and ongoing assessment data, means that schools are often "data rich" but some teachers said they don't always have time to properly examine assessment data. The consensus from one group was that they must be more selective in choosing which data are most relevant for a child's educational planning. Making assessment data easily accessible in files or on a computer, and presented in a way that is easy to follow, was also highlighted as a priority.

A practitioner who works in further education remarked that many of the existing assessments were suitable for early years or primary school aged children but there was little in terms of assessment for teenagers or college-aged individuals on the autism spectrum:

"At the moment there are very different sets of measures used in school and in FE. We don't use p-scales in FE and nor should we because you are looking at different things....But the kind of ability levels that we are currently describing for these learners in FE aren't a fair reflection of their ability."

6.2.3 Interviews with academics, commissioners and decision-makers

A range of additional stakeholders were asked about their views on the usefulness of current assessment measures and recommendations for improvements.

A leading academic in the field of SEN commented on P Scale assessments and said that for children with autism it is important to look beyond these restricted measures and towards assessing social and emotional issues as well. A further comment was that P Scale assessment data are sometimes incorrectly interpreted:

"Ofsted inspectors don't understand. They see progress as being linear and based on raw statistics. So when a child moves from P3 to P5 in a particular timescale, that's what they consider progress. But there might be a young person who stayed at P3 for a whole year but has made significant progress in other ways."

This was supported by a commissioner of education, who suggested that official assessments like P Scales should be tailored more to the profiles of children with autism:

"It would be good if we could look into making assessments more autism friendly and we could all decide how we use them across all autism provisions. What we currently don't do is to look at assessing what you need to have the best quality of adult life. If you don't have autism that's accepted and understood but with people with autism they [teaching staff and inspection teams] **don't do enough work to assess how you plan towards independence."**

Many schools are beginning to think beyond P Scale assessments to develop their own assessment measures and how they can more clearly define a baseline assessment, describing where a child is starting from and what areas of skill development they need to focus on. One suggestion from an interviewee was that groups of schools should work together to devise frameworks and assessment tools that are suited to demonstrate progression in young people with autism.

One interviewee pointed to the fact that teaching staff and inspectors often see assessment data as the end point rather than letting the data inform where the child may be struggling or how to revise educational curricula:

"We assess at the end of primary school -key stage 2- with the SATS. But very few secondary schools then take this data and think 'ok what can we do to move them on from here. They just start all over again."

The interviewee concluded that too often data is collected for the sake of it, rather than thinking **"what can we do with it to help the child progress in the right direction".**

A representative of the school's inspectorate commented that there are challenges in teachers communicating children's progress to Ofsted:

"I used to say to people: tell me about a learner, pick any learner you like, tell me what he's learnt to do, what were the big achievements. And people would give you these gems of things, tell you about the enormous amount of things that have changed for this one learner but often when you then look at the paperwork and look at what they are actually tracking… they're not reporting any of that! They don't know how to reflect what really happened in what they report to Ofsted."

One interviewee who works closely with parents on legal issues around statements for educational needs highlighted the fact that children are often assessed repeatedly and that it is not always clear to the parents what the purpose of this data collection is as the results are rarely communicated to them. However, the importance of assessments was made clear by this interviewee for deciding on the content and direction of services:

"If you don't have assessments you either have arbitrary decision making (e.g., everyone gets this many hours of support) or you have a system where everybody gets what they ask for. Families get very frustrated by repetitious assessment and I understand why but assessment is the starting point. The problem is that the assessment system isn't capturing properly the child's needs."

6.3 Assessment measures and how they relate to adult outcomes – Summary

Teaching staff typically collect data using a range of standardised and bespoke measures that assess children's progress towards specific outputs. Survey respondents reported both on assessments to measure skills that relate to autism (e.g., measuring sensory issues or social skills) and on general measures of attainment in relation to National Curriculum and P-Scale targets. Teaching staff commented on their difficulty to report on aspects of attainment that fall outside the National Curriculum and requested greater flexibility in the data they could submit as part of the inspection process.

Despite the large amount of assessment data collected in schools, it is often unclear how this information is used to facilitate educational planning for pupils with autism. Teaching staff also have limited time to score and interpret these assessments or enter data into software or in-house databases. Practitioners expressed the wish to share information across schools (including between mainstream and specialist schools) on the assessments they are using and what works well.

7. Conclusion

It was important to note from this research that what individuals without autism regard as good adult outcomes should not be imposed on people with autism. At the core of defining good outcomes for people with autism should be sensitivity to individual variation in what is desired. Of course this is more straightforward for people who are verbally able enough to express their opinions on their outcomes, but there is a need to adopt innovative approaches to facilitate the consultation of individuals on the spectrum who have no or limited speech. This should include a closer cooperation with parents or carers of these individuals where appropriate.

This research found some consistency across stakeholder groups in what were reported as desired adult outcomes for people with autism and in many ways these are the same outcomes we would expect education to be universally aiming for. However, the autism spectrum is broad and there existed significant variation amongst contributors to this research as to what should and can be achieved by people with autism. So in all cases of educational planning for good adult outcomes the opinions of the young person with autism should be central in guiding this process.

A clear message needs to be sent to teaching staff, school inspectors, local authorities, commissioners and central government that too little is known about whether current educational planning for children with autism is directed towards reaching good adult outcomes. There is also a lack of good examples of tracking children and young people with autism into adulthood to learn about their outcomes and whether there were aspects of educational practice that hinder or facilitate them meeting good outcomes.

Stakeholders who took part in this research reported a number of barriers within educational practice that are restricting many children and young people on the autism spectrum reaching good outcomes:

1. Lack of autism expertise amongst teaching staff;
2. Young people with autism not acquiring basic independent living and self-help skills;
3. Young people with autism not attaining basic academic skills (e.g., reading and writing);
4. Young people with autism being bullied at school and subsequently developing low self-esteem;
5. Schools failing to provide young people with autism access to both work experience and appropriate career advice.

In many ways schools are "data rich" and teaching staff use a range of assessment tools to measure progress but this precious resource is not being used optimally to observe and report on progress the child is making towards reaching targets and outcomes.

All individuals with autism are entitled to a good education and a good quality of life. What is clear from this research is that the pattern of outcomes for many adults with autism does not match with the hopes and aspirations children and young people have for themselves. More can and should be done to make certain that education is planned out for people on the spectrum so they can reach their full potential and lead fulfilled lives.

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9. Appendices

1. Online surveys

1.1 Survey for children and young people with autism

The survey for children and young people focused on questions about what they liked (or did not like) about school or college and what they would like to do in adult life. The survey was divided into 4 main sections:

(1) Background information: gender, age and type of school attended now and previously (from a list of options that could be ticked);

(2) Experiences at primary hool: a set of five statements about school (e.g. I felt that my teachers helped me with my work in class) that asked about support from teachers and other children. Responses could be made by ticking an answer on a 5-point scale: 'yes definitely'; 'I think so'; 'not really sure'; 'I don't think so'; 'definitely not'; or 'this does not apply to me'. This section also included two 'open' questions which asked children to write about the best and worst things about school.

(3) Experiences at secondary school (this section could be skipped if not applicable – i.e. the child was still in primary school): a set of statements about school similar to the primary section but in addition asking about preparation for adult life e.g. 'I feel that my teachers are planning for my future as an adult'. Again, there was space here in response to open questions to say what the best and worst things are about secondary school. There was a further 4 statements (optional) that could be answered here if the respondent was leaving school / college in the next 12 months; these asked about planning, preparations and choices for the next step.

(4) What you want out of life: three spaces for children to write in 'My hopes and dreams for when I am an adult'; and then a further two spaces to write in comments about whether school / college is helping in reaching those hopes and dreams and what they are or could be doing to help. The final question asked whether the child had received help when completing the survey.

1.2 Survey for adults on the autism spectrum

The survey for adults on the autism spectrum was divided into 5 main sections:

(1) Background information: age; gender; county of residence; diagnosis; and any additional disabilities or difficulties; type of school attended during primary and secondary phases; and current situation regarding training/education/employment.

(2) How well secondary school (or the place where learning took place from 11-16 years) prepared the respondent for the things they did when they left school; these questions required respondents to rate whether they had:

a. enough information to decide what they wanted to do when they left school;
b. the same choices and opportunities as others; and
c. achieved the qualifications they wanted.

(3) Most and least helpful things at school/college that helped the respondent as an adult; these were open questions so respondents could write anything in here that they felt was relevant.

(4) Current living arrangements; whether the respondent receives benefits of any kind, and friendships and social activities.

(5) Current ratings of satisfaction with different parts of the respondent's life since leaving school or college and whether they think they had received enough support.

Ratings in sections 2 and 5 used a 5-point Likert response scale: 'yes definitely'; 'I think so'; 'not really sure'; 'I don't think so'; 'definitely not'. There was also a 'this does not apply' box that could be ticked for each statement.

At the end of the survey there was an 'open' question which asked: Finally, here is space for any further comments you have about any of the questions asked above or about how the hopes and needs of people on the autism spectrum can be better supported.

The survey was revised and finalised following detailed feedback from a senior practitioner who works with adults on the autism spectrum.

1.3 Survey for parents of children and young people on the autism spectrum

The survey for parents of children and young people (under the age of 18) on the autism spectrum was divided into five main sections:

(1) Background information was gathered on the parent: age; gender; relative status; county of residence (selected from a list of options)

(2) Information was collected on the parent's child: age, gender, educational status and diagnosis (selected from a list of options)

(3) Parents were asked to write three important outcomes that they hoped their child would achieve or have in their life in the next 12 months.

(4) Parents were then asked a similar question about the three most important outcomes for their child's overall adult life.

(5) Parents were asked about how teaching staff communicate to them about how their child is getting on and whether parents are included in educational planning for their child. Parents responded to nine statements about these issues, using a 5-point Likert scale (from 'strongly agree' through to 'strongly disagree').

1.4 Survey for parents of adults on the autism spectrum

The survey of parents of adults (aged 18 and over) on the autism spectrum was set out across the same five sections as the survey for parents of children with autism, but with some adjustments:

- In section (2), parents were asked about their son/daughter's current employment or education status and about qualifications attained.
- In section (5), if their child was not at school/college anymore, parents were asked to comment retrospectively on communication with teaching staff and aspects of educational programming when their child was still at school or college.

1.5 Survey for school/college practitioners

This survey was designed for practitioners working with young people on the autism spectrum at a school or college (or as a home-education provider) in England. Questions were divided into 5 sections covering:

(1) Respondent demographics (gender; profession).

(2) Characteristics of the school/college and the children/young people they worked with (type of school/role; age of pupils; geographical location).

(3) Which assessments are regularly used for children/young people on the autism spectrum (from a list of common assessments, with the ability to add and comment on additional assessments).

(4) Practitioners were able to indicate which assessments they found most useful for measuring language and communication ability, progress towards independence, social skills, pupil's ability to manage stress and behaviour, pupil's ability to manage sensory issues, and for planning long-term adult outcomes.

(5) Practitioners were asked about the frequency and format of how findings from the assessments used were feedback to parents.

2. General protocol for focus group discussions

Overall aim of the group session: to elicit views and experiences from all group members on the main questions under discussion.

Underlying principles:

- we are not aiming for consensus - all views are welcome;
- everyone should be given the opportunity to contribute their views;
- the group session should feel like a safe space in which views can be shared and disagreements raised without judgement;
- the same questions should be asked in each group but, depending on the time available and nature of the group, the methods used to ask the questions and obtain feedback may differ.

The facilitator's job is therefore to ensure tactics are deployed to support all participants in contributing to the session and to make them feel comfortable about doing so. This means that clear ground rules should be set at the start and the facilitator needs to be assertive in managing the overall agenda as well as the inputs from individuals. The facilitator also needs to ensure that the views of participants are captured effectively, either through 'dynamic recording' of data (e.g. using clearly displayed notes on flip charts or board that capture comments as they occur) and / or via video or audio recording that can be scrutinised afterwards.

The facilitator can help people to feel at ease by:

- sending the agenda, and questions, to participants before the session so that they know what they are going to be asked, and making this as accessible as possible;
- giving them a warm welcome when they arrive and having refreshments available;
- starting on time and sticking closely to the agenda (which should be shared with the group);
- ensuring at the start that everyone says something early on (eg. introduces themselves) as this can help participants to know that they do have a voice and it will be heard and respected by others;
- making clear that everyone will have a chance to contribute to the discussion; ways of doing this can be made explicit eg. '…to start with I am going to ask each of you in turn to say your name and your interest in coming along today. I'll start and then we'll go clockwise around the group. Everyone will have a turn so please do not interrupt when someone else is talking…';
- make sure the group is doing most of the talking and you are doing most of the facilitating!

Suggested main agenda

1. Welcome and overview of project
2. Consent to take part / reminders about withdrawal and confidentiality (no names used outside the room; comments will appear anonymously in reports etc).
3. Introductions (taken in turns around the group)

- You + your family
- Why interested in coming today?

4. Ground rules

- Listen to and respect others' views
- Give others space to contribute views
- Keep views within this room
- Others? [Note: it's worth tackling mobile phones at this stage – either switch off or change to silent]

5. Questions for discussion: e.g. Parent focus groups

(1) Assessing and communicating progress: What information are you given about how your child is progressing at school?

- For example, school reports; grades / levels achieved in particular subjects; language reports; social and emotional wellbeing; independence and autonomy; home-school books; parents evenings; other?
- When / how / by whom is information provided?

(2) Adequacy of information about progress: How is the information you receive about your child's progress helpful?

- Does this information tell you what you want to know?
- What information would you like to receive but currently do not?
- When / how would you like to be told this information?

(3) Adequacy of information about progress: Does this information tell you what you want to know about your child's progress?

- What information do you currently receive that is helpful?
- What information would you like to receive but currently do not?
- When / how would you like to be told this information?

(4) Aspirations and outcomes: Thinking about the future, what would you consider to be successful outcomes for your child in adult life?

- What do you hope they will be able to achieve?
- How does the information you receive about your child's progress link with the outcomes you think are important?

(5) Next steps [what happens with the information now?]

(6) Thank you and finish

3. Parent survey content analysis tables

3.1 Parents of children and young people with autism: hopes for the future

Results of the content analysis from parents of children on the autistic spectrum -to the questions (1)"What I would like my child on the autism spectrum to have in his/her life in the next 12 months is…" and (2) "What I would like my child on the autism spectrum to achieve or have in his/her adult life is…"

Overall category	Hopes for next 12 months N (% of responses)	Hopes for adult life N (% of responses)	Subcategories	Hopes for next 12 months N (% of responses)	Hopes for adult life N (% of responses)
Independence	113 (11.5%)	175 (18.8%)	Independence/become more independent	23 (2.3%)	145 (15.6%)
			Develop a specific life skill. E.g. using public transport, cooking etc.	75 (7.6%)	14 (1.5%)
			Ability to organise self. e.g. make own social arrangements with friends etc.	6 (20.6%)	7 (0.8%)
			To be financially secure	3 (0.3%)	0
			Live in own home	0	9 (1%)
Socialisation/ Relationships	208 (21.1%)	230 (24.7%)	A social life	11 (1.1%)	21 (2.1%)
			Improved relationships with peers/ a friend	76 (7.7%)	4 (0.4%)
			A true friend/ meaningful friendships	6 (0.6%)	59 (6.3%)
			A support network of non-family members	0	19 (2.0%)
			Girlfriend/boyfriend	0	46 (4.9%)
			A family/children of their own	0	22 (2.3%)
			Develop social skills	103 (10.4%)	25 (2.7%)
			To be accepted/valued/included in community	8 (0.8%)	34 (3.7%)
			Improved family relationships.	4 (0.4%)	0
Physical Health	54 (5.5%)	3 (0.3%)	Improve health	7 (0.7%)	3 (0.3%)
			To have a better/specialist diet	11 (1.1%)	0
			Better physical ability	7 (0.7%)	0
			Sort out specific physical health issues	7 (0.7%)	0
			Sleep problems	5 (0.5%)	0
			Learn/improve a sports activity	17 (1.7%)	0
Non-education services	37 (3.8%)	55 (5.9%)	Help from service providers when needed (non-specified)	3 (0.3%)	14 (1.5%)
			Get support for specific stated problem (s)	34 (3.5%)	2 (0.2%)
			Supported living placement	0	29 (3.1%)
			To have support when parents are no longer able to look after offspring	0	10 (1.1%)
Language skills	68 (6.9%)	20 (2.1%)	To improve language skills	59 (5.0%)	20 (2.1%)
			To start talking/communicating	9 (0.9%)	0

Overall category	Hopes for next 12 months N (% of responses)	Hopes for adult life N (% of responses)	Subcategories	Hopes for next 12 months N (% of responses)	Hopes for adult life N (% of responses)
Emotional wellbeing	175 (17.8%)	237 (25.5%)	To be happy	47 (4.8%)	114 (12.2%)
			Increased emotional wellbeing	9 (0.9%)	0
			Increase confidence/self esteem	31 (3.1%)	10 (1.1%)
			Develop emotional maturity	15 (1.5%)	21 (2.2%)
			To control/reduce anxieties or obsessions	34 (3.5%)	9 (1%)
			Child to have a greater understanding.	18 (1.8%)	0
			Awareness/acceptance of own autism spectrum condition	11 (1.1%)	8 (0.9%)
			Child able to face challenges in life/embrace life	7 (0.7%)	0
			Child to pursue own interests	3 (0.3%)	15 (1.6%)
			Child to reach their full potential	0	48 (5.2%)
			To be safe	0	12 (1.3%)
Challenging	34 (3.4%)	0	Stop specific challenging behaviours	13 (1.3%)	0
			For child to learn how to control own emotions/behaviour	21 (2.1%)	0
Education	266 (27%)	0	Good exam results/take exams	19 (1.9%)	0
			To get into class/school of choice	27 (2.7%)	0
			To cope with/enjoy school/not be bullied	51 (5.2%)	0
			To sort out issues around statement of educational needs	10 (1.0%)	0
			Achieve academic potential	15 (1.5%)	0
			To get/remain in a good education	14 (1.4%)	0
			Achieve specific academic skill /make academic progress	86 (8.7%)	0
			To get needed support/understanding from school	41 (4.2%)	0
			ABA therapy	3 (0.3%)	0
Transition	30 (3%)	3 (0.3%)	Get prepared for secondary school	16 (1.6%)	0
			Smooth transition to adulthood	8 (0.8%)	0
			Child to know what they want/have an idea of future direction	4 (0.4%)	0
			Support in placement/future career.	2 (0.2%)	3 (0.3%)
Work life	0	208 (22.3%)	A job	0	72 (7.7%)
			A meaningful job/job they enjoy	0	102 (11%)
			Ongoing education/learning in adulthood	0	

3.2 Parents of adults with autism: qualifications and education/work status

This table shows the highest level of qualification achieved, or currently completing, and the current work status of adult offspring.

Highest level of qualification achieved/ currently studying for	N (%)	Work/education status- Current situation	N (%)
No qualifications	19 (27.5%)	Not in work or education	19
Up to 4 state qualifications (e.g. GCSE)	14 (20.3%)	Studying at a College or University	23 (33.3%)
5 or more state qualifications	1 (1.4%)	Supported to do voluntary work or a skills placement	1 (1.4%)
Vocational qualifications	5 (7.2%)	Supported to do a full-time paid job	1 (1.4%)
AS or A Levels	3 (4.3%)	Supported to do a part-time paid job	1 (1.4%)
Higher Education diplomas or certificates	3 (4.3%)	In a full-time job (with no additional support)	3 (4.3%)
Undergraduate degree	11 (15.9%)	In a part-time job (with no additional support)	4 (5.8%)
Post-graduate degree (e.g. Masters or Doctorate)	2 (2.9%)	Other	9 (13%)
Don't know	2 (2.9%)		
Missing data	9 (13%)		

3.3. Parents of adults with autism: hopes for the future

This table shows the results of the content analysis from parents of adults with autism to the questions (1) "What I would like my son/daughter on the autism spectrum to have in his/her life in the next 12 months is…" and (2) "What I would like my son/daughter on the autism spectrum to achieve or have in his/her adult life is…"

Overall category	Aspirations for the next 12 months N (% of responses)	Aspirations for adult life N (% of responses)	Subcategories	Aspirations for next 12 months N (% of responses)	Aspirations for adult life N (% of responses)
Independence	29 (18.8%)	24 (16.7%)	Independence/ become more independent	8 (5.2%)	17 (11.8%)
			Develop a specific life skill. E.g. using public transport, cooking etc.	19 (12.3%)	5 (3.5%)
			Live in own home independently	2 (1.2%)	2 (1.4%)
Socialisation/ Relationships	39 (25.3%)	43 (29.9%)	A social life	12 (7.8%)	4 (2.8%)
			True/meaningful friendships	14 (9.1%)	14 (9.7%)
			Informal support network of family/ friends etc.	0	5 (3.5%)
			Develop social skills	4 (2.6%)	1 (0.7%)
			Girlfriend/ Boyfriend	7 (4.5%)	11 (7.6%)
			Own family/ children	0	3 (2.1%)
			To be accepted/ valued/included in community	2 (1.2%)	5 (3.5%)
Non-educational services	25 (16.2%)	14 (9.7%)	Live in residential placement/with support	9 (5.8%)	6 (4.2%)
			Get support for specific stated problem (s)	13 (8.4%)	5 (3.5%)
			Easier access to services, for parents	1 (0.6%)	1 (0.7%)
			Autism specific service	2 (1.2%)	0
			To have support when needed	0	2 (1.4%)

Overall category	Aspirations for the next 12 months N (% of responses)	Aspirations for adult life N (% of responses)	Subcategories	Aspirations for next 12 months N (% of responses)	Aspirations for adult life N (% of responses)
Work life	34 (22.1%)	25 (17.4%)	Get employment/a job	15 (9.7%)	0
			Supported employment/ voluntary work	3 (1.9%)	3 (2.1%)
			Purposeful employment/ a job they enjoy	4 (2.6%)	18 (12.5%)
			On-going education	0	4 (2.8%)
			Complete current educational course	12 (7.8%)	0
Emotional Wellbeing	22 (14.3%)	38 (26.3%)	To be happy	8 (5.2%)	20 (13.9%)
			Increase confidence/self esteem	9 (5.8%)	2 (1.4%)
			Develop emotional maturity	1 (0.6%)	4 (2.8%)
			To control/reduce anxieties	3 (1.9%)	2 (1.4%)
			Fulfilling life/pursue own interests	0	6 (4.2%)
			To be safe in community	1 (0.6%)	4 (2.8%)
Financial skills	5 (3.2%)	1 (0.7%)	Financial independence	4 (2.6%)	1 (0.7%)
			Financial understanding	1 (0.6%)	0

3.4. Parents of children/young people and of adults on the autism spectrum: opinions on communication with teaching staff

This table details parent's responses to the 'experiences of communicating with teaching staff' section of the survey. The below figures are in percentages of the sample of parents endorsing each point of the agreement scale for each rated item. Missing data have not been included when calculating percentages.

	School gave regular information on child's progress		School gave good quality information on child's progress		School listened to child about developmental targets (short-term outcomes)		School listened to parent about developmental targets (short-term outcomes)		School worked with child on deciding what child wants to achieve as an adult		School listened to parent when deciding what child could achieve as an adult		School did a good job of focusing on appropriate skills and qualifications needed for adulthood		It's important for me to attend child annual review meetings		The annual review process gave me a good idea of their progress towards important outcomes	
	Child[1]	Adult[2]	Child[1]	Adult2	Child[1]	Adult[2]	Child[1]	Adult[2]	Child[1]	Adult[2]	Child[1]	Adult[2]	Child[1]	Adult[2]	Child[1]	Adult[2]	Child[1]	Adult[2]
Strongly Agree	27.9	9.8	20	9.8	21.7	7.8	23.1	6	9.4	7.8	9.8	9.8	12	9.8	79.6	60.7	39	10
Agree	37.5	39.2	36.9	17.6	27.0	15.7	32.5	22	15	7.8	15.8	15.7	22.8	21.2	5	5.9	24.5	28
Neither agree nor disagree	11.1	7.8	14	19.6	18	15.7	15.9	14	19.1	5.9	22.4	13.7	15.2	21.2	0.6	1.9	11	14
Disagree	15.8	21.2	18.8	25.5	18	19.6	15.6	18	15.4	23.5	12.6	15.7	15.2	0.7	0.3	9.8	5	10
Strongly Disagree	5.3	21.2	6.9	27.5	8.4	37.2	10		13.5	47	12	43.1	12.6	0.6	0.1	0	5	22
Not applicable	2.3	–	2.8	–	6.8	3.9	2.8	4	27.6	7.8	26.5	1.9	21.5	0.7	14.1	21.2	15.4	16

[1]Responses of parents of children on the autism spectrum [2] parents of adults on the autism spectrum

Designed by Genium

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