autism education trust

# Outcomes

# Educational provision and outcomes for people on the autism spectrum

## Executive summary


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**‘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.’**

# Introduction

**Autism** is a lifelong developmental disability that affects how a person communicates with and relates to other people and can lead to rigid and repetitive ways of thinking and behaving. Once thought to be a very rare disorder, it is now estimated that around 1 in every 100 children and adults in the UK have autism[1]. Although many people with autism have an additional learning disability, a substantial proportion are of average or advanced intellectual abilities. People with autism also have increased rates of mental health problems (e.g. anxiety, depression) and co-occuring medical conditions (e.g. sleep difficulties, epilepsy).

**Educational provision for children and young people with autism.** There are a number of options in terms of educational provision for pupils on the autism spectrum including: mainstream schools with or without specialist resource bases and support; autism-specific special schools as well as those with a broader intake of children and young people with a range of different support needs; and home-schooling. Which type of placement best meets the needs of a young person with autism will depend on his or her individual skills and difficulties, as well as the family situation. Schools vary widely in quality and expertise and careful assessment of both the pupil and the school is needed in order to maximise the chances of a successful placement.

**Outcomes for adults with autism.** Most research, as reflected in the reports commissioned as part of the National Strategy for adults with autism (DoH, 2010 Fulfilling and Rewarding Lives) indicates poorer conditions in adult life for people with autism compared to their peer group in terms of employment, accommodation, social inclusion and mental health. In consequence, there has been an increasing call for public services in England to be planned around the needs of adults with autism across the lifespan.

**The Autism Education Trust (AET)** is dedicated to coordinating and improving education support for all children and young people with autism in England. In early 2011 the AET commissioned a piece of research to explore **how current educational provision in England is preparing children and young people with autism for good adult outcomes.**

[1] We refer to people "with autism" or "on the autism spectrum" to include all those individuals who have a diagnosis of autism, Asperger and Pervasive Developmental Disorder Not Otherwise Specified.

## The central questions asked as part of this research 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?**

## Methodology

Data were collected via a **literature review** and consultation with key stakeholder groups, using **online surveys**, **focus group discussions** and **individual interviews**. Multiple methods were used in order to collect a wide range of opinions and experiences.

## In total 1019 stakeholders contributed to the research

- 900 people from across England[5] responded to one of five **online surveys**, tailored specifically to each stakeholder group: 30 young people with autism; 69 adults with autism; 382 parents of children and young people with autism; 70 parents of adults with autism; 349 practitioners working in schools and colleges.

- 35 parents, 4 young people with autism[6], 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.

- A further 46 people took part in **individual interviews** either face-to-face or over the telephone. These included: young people and adults with autism; parents of adults with autism; professionals from a range of sectors and expertise (academics, headteachers, teaching staff, SENCos, speech and language therapists, occupational therapists, educational psychologists, voluntary sector staff, education service providers, regulators and individuals representing professional bodies).

[5] Data on the geographical distribution of respondents show that our survey has reached respondents in all except 2 English counties and boroughs.

[6] Most of the young people with autism we spoke to in schools preferred to be interviewed individually.

# Key findings

## 1 What do stakeholders regard as a "good outcome" for adults from across the autism spectrum?

**"(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."** [Parent of a young adult with autism and severe learning difficulties]

**The main consensus across stakeholders was that** a 'good adult outcome' should always be considered within the context of individual needs and aspirations. Although a 'typical' good outcome including employment and independence was desired by some young people and adults as well as by parents, this was not the case for all. It should not be assumed that that which is a good outcome for someone without autism is necessarily the same for someone with autism.

**Enabling a person with autism to make their own choices is key.**

**"People keep asking me 'don't you feel lonely, wouldn't you like to meet more people?'... If they didn't keep asking me about having friends I would be fine but the more they go on about it the more useless I feel".** [Adult with autism in her thirties]

Difficulties finding and/or keeping employment, problems in finding somewhere to live and difficulties in social relationships were frequently cited problems among adult survey respondents, most of whom were diagnosed with Asperger syndrome in adulthood. 48 out of 55 adults who responded to this question (87%) agreed with the statement that being on the autism spectrum hindered them from doing some of the things they wanted to do in life. Access to the right support when needed was identified as key to a good quality of life.

With regard to the hopes and aspirations of parents for their children with autism as adults, the top priorities were: emotional wellbeing (25%), ability to build social relationships (25%), employment (22%) and developing independent living skills (19%).

Focus groups and individual interviews frequently identified the importance of enabling people with autism to have choice and control over their lives:

**"In my experience the one most powerful thing that anyone can do to help an autistic person is to support them in living autonomously – i.e. that their life is defined by their own life choices. [...] Needing support and help in a person's life should not EVER be used as a reason to deny a person's autonomy & independence."** [Adult with autism in her fifties]

### Recommendation

- **Schools** and **other service providers** should make every effort to consult all young people with autism, including those with limited communication means, about their desired outcomes for adult life. This consultation should include, where appropriate, the opinions of parents and carers.

## 2 Are current policies and practice for educating children with autism designed with planning for good adult outcomes in mind?

**Central to educational planning should be setting long-term targets that are realistic and revised periodically after a consultation with the child or young person with autism and, where appropriate, parents and carers.**

**"Having a goal makes the biggest difference. We are working with the students on a visual pathway where it is very clear where they are now, where they want to go to and precisely what steps are in between. [...] It is a way of helping them understand how the curriculum content relates to their life".**
[Headteacher of a special residential school for 5-19 year olds]

There is a lack of policy guidance for teaching staff to carry out educational planning towards meeting long-term targets and good adult outcomes. Practitioners are more inclined to plan short– to medium– term targets or to meet particular outputs for when the young person leaves their provision (e.g. end of primary school). Parents reported finding it difficult to think too far ahead in terms of long-term planning into adulthood as there was so much uncertainty about their child's developmental trajectory. Some respondents spoke of the need to begin educational planning early, for aspirations to be realistic and for it to be guided by the voice and opinions of the child or young person.

**"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?"**
[A commissioner of education services]

Lack of coordinated transition planning was noted by many interviewees, particularly when young people are moving from school into further/higher education or the workplace:

**"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."**
[Adult with autism in his early twenties]

Many adults with autism reported leaving school feeling unprepared for the next steps. Specific complaints expressed by 59 adults with autism responding to our survey were: lack of information on what to do next (61%); lack of opportunity to achieve the qualifications they wanted (58%); not being provided with a number of options to choose from when leaving school (52%); limited choices compared to other young people (48%).

### Recommendations

- **Parents and school practitioners** should break down longer-term targets (through school and into adulthood) into small understandable steps and a clear route to achieving these targets should be presented to the young person. Longer-term targets should be revisited annually and adjustments made based on the pupil's current opinions, where appropriate, and their progress.
- **The Autism Education Trust** should survey the opinions of school staff, as well as further and higher education practitioners, regarding how they might better support young people on the autism spectrum into the workplace. Based on these data sets, specific recommendations should be made on how best to help young people with autism access work experience and to ease the transition from school to work (e.g. working with the employer around autism awareness).

**There was a strong call for there to be greater flexibility in terms of what can be taught as part of the curriculum.**

46% of the 349 respondents to the practitioner survey were working in special or specialist services and 37% worked in mainstream provision. Most respondents set targets weekly (59%), mainly based on classroom observations, and monitoring of progress and revision of targets was most frequently made using Individual Education Plans (IEPs). Teachers and teaching assistants were typically involved in the setting of targets.

The overall goal for most was to teach towards reaching National Curriculum levels or P-levels for those pupils working below the National Curriculum level 1. A number of respondents felt constrained by these criteria and noted that in order to reach meaningful outcomes for pupils with autism they had to be creative in modifying the National Curriculum to the individual pupil's needs. Practitioners recognised the importance of academic skills but also voiced the need to broaden the National Curriculum to focus on social and life skill development, particularly in mainstream settings.

**"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".**
[Speech and language therapist working in an autism outreach service]

The need for increased flexibility in terms of when education goals should be completed was also noted. For example, a student may be unable to complete GCSEs at 16 years but be well able to do so at 18 and should be given the opportunity to do so. Adults with autism noted the need for a stronger focus on the acquisition of independence and study skills (e.g. learning how to organise homework; revise for exams etc.) during their school years.

## Recommendation

- The **Department for Education** should provide written guidance on how teachers, particularly in mainstream settings, can find the right balance between teaching pupils with autism key academic skills and teaching them skills that fall outside of the National Curriculum (e.g. independent living skills, social and emotional understanding).

**Children with autism require support during school to avoid the long-term emotional damage that can be caused by bullying. The importance of having an early diagnosis and help for peers and school professionals to understand the diagnosis was highlighted by many respondents.**

**"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."**
[Adult with autism in his early twenties]

Many respondents with autism described the debilitating effects of bullying during their time at school, which affected their academic achievement, mental health, self-esteem and outcomes in adult life. Indeed, 38 out of 70 adults surveyed (54%) reported having a mental health difficulty.

Adults with autism we spoke to felt that teachers could have done more to protect them from bullying and that staff should aim at providing a "safe haven" within the school.

Individuals who had not been diagnosed until adulthood spoke of how knowledge about their autism during the school years would have helped them to understand why they felt different. Younger people noted that having a greater knowledge of their autism could help them to better understand their role in social relationships.

**"Having some sort of a mentor would have been ideal. Preferably another Aspi, who's been there, done it... I think that would have helped me a lot. We should employ autistic adults who had an experience they can share".** [Adult with autism in his thirties]

## Recommendations

- **School staff** should be trained to be aware of vulnerable pupils and the situations - particularly in mainstream settings – in which they are at risk of bullying. The possibility of offering a "safe haven" for pupils with autism should be considered.
- **Schools** should include time within their "flexible" curriculum for pupils with autism to develop their self-awareness and to discuss their diagnosis, should they wish to.
- **Local authorities** should employ adults on the autism spectrum as consultants to work with people with autism in schools. They could be talking about their experiences; acting as mentors or role-models to demonstrate positive outcomes in adult life.

**The increased risk of exclusion from school and the need for improved communication amongst teaching staff and between teachers and parents/carers was highlighted. Children, young people and adults with autism felt that some teaching staff lacked an understanding of their problems.**

**"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 with autism in his late teens.]

Young people with autism expressed a desire for or school staff to give greater consideration to their learning needs; adults noted that more specialist support from teachers and SENCos during their school years would have given them a better chance of success.

**"The reason why they didn't do anything for my special needs was that there was just one SENCo for my whole school and it was a big school and there were people who had much greater needs. They only took notice of me in the last couple of months when I lost it and by then it was too late"** [Adult with autism in his twenties]

Some respondents suggested that there should be a member of staff within each school who is an "autism expert" to advise teaching and senior management staff (especially from mainstream schools), as well as pupils, on questions about autism. The autism expert could play an important consultation role if pupils 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.

Improved communication amongst school staff was also highlighted. Feedback from Learning Support Assistants (LSA) indicated that they felt their opinions were often under-valued. For example, current funding arrangements made it difficult for them to attend educational planning meetings for the pupils they worked with. Parents and carers were generally positive about communication with teaching staff, especially in specialist provision. However, some questioned the value of generic reports particularly from mainstream schools, which provided little detail on either what support was needed for pupils to achieve progress or why they were failing specific targets.

## Recommendations

- **Local authorities** should support the training of a member of staff to work as an "autism expert" across a network of mainstream schools, with the longer-term objective of employing an autism expert in every mainstream school.
- **Senior school management** and teaching staff should regularly involve Learning Support/ Teaching Assistants in educational planning for pupils with autism. School budgets should be adjusted to fund the attendance of these members of staff at educational planning meetings.
- **School** reports should be more individualised with detailed information about pupil progress and educational targets.

**Educators lack information on students' longer term outcomes.**

**"We would be very interested to have information about where the pupils we work with go onto in the longer term. It would help to inform what to focus on while they are with us."**
[Head of a secondary residential special school]

There is a lack of systematic data on what happens to young people after they leave school – how successful the transition from school has been or what students' long term outcomes are. Such data would be particularly valuable for informing educational planning for future students.

## Recommendation

- The **Department for Education** should commission research which requires a group of Local Authorities to follow at least a subset of young people with autism into adult life. This would allow an assessment of the factors influencing outcomes.

# 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?

**Schools typically use a range of standard and bespoke assessments to measure the skills and progress of pupils with autism. However, this rich data source is not always collected with sound educational planning in mind.**

**"Capturing and reporting progress appropriately is probably one of the most challenging parts of special education, particularly with children who have autism".** [SEN Academic]

Practitioners identified a wide range of measures used with children and young people on the autism spectrum. In addition to the required National Curriculum or P-level descriptors, a large proportion of practitioners reported assessing autism-specific characteristics such as pupils' sensory profile (41%) and their use of the Picture Exchange Communication System (PECS; 39%). Respondents also listed which assessments they thought were most useful in measuring progress towards specific educational targets (see Table 3 in the full report). Many of the measures assessing National Curriculum and P-level attainment were considered ill-suited for planning or monitoring educational progress in children and young people with autism and hence a wide range of 'bespoke' assessments was in use.

**"It is demoralizing as a teacher to see the children make huge progress in skills that are vital to their life but yet not show as progress because it's not on the NC or P levels".** [Teacher from an autism resource base]

Teachers are required by Ofsted to assess pupils using National Curriculum and P-level descriptors. However, 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.

**"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."** [SEN Academic]

Despite the large amount of assessment data collected in schools, it is unclear how this information is used to facilitate educational planning for pupils with autism. Teaching staff also have limited time to score these assessments or 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.

## Recommendations

- **Schools** should look beyond what is measured by National Curriculum level descriptors and be encouraged to include data that are collected as part of the school's standard or in-house assessments (e.g. on social-communication and independent living skills; sensory sensitivities).
- The **Autism Education Trust** should lead on a consultation with Ofsted regarding current training on autism within their SEN training. This consultation will look to provide updated content and the opportunity for inspectors to access more comprehensive training packages on autism.
- **School practitioners** should systematically review their current systems of pupil assessment and collaborate with other schools as part of this review. This process should ask:

– Is too much or too little information being collected?
– How are data being stored, analysed and interpreted?
– Is software available to assist in the better use of data?
– How are data sets used to track pupils' progress and inform revisions to their curriculum?
– Can improvements be made in how data are reported to parents and carers?

## Conclusion

A central tenet of education is to equip young people with the skills to reach their full potential. Given the challenges that individuals with autism face in adult life it is vital that educational provision for children and young people with autism is planned early and with a mind to them achieving their desired outcomes.

One important first step is to place the young person with autism at the centre of decisions made about what they want to aim for in their adult life and for these goals to be reviewed regularly by practitioners with expert knowledge of autism.

Beyond that, it is critical for there to be cross-sectoral agreement on ways of working within a flexible and individually tailored curriculum to provide pupils with autism with the range of necessary skills to achieve such aims. This extended curriculum should be ambitious, provided and assessed by well trained staff, and delivered in a secure and engaging environment.

Progress should be measured using nationally accepted, as well as bespoke, assessments to track the pupil's behaviour and progress in a range of domains.

Ultimately, research that traces the development of pupils with autism into their adult life would provide a rich understanding of the relationship between educational provision and adult outcomes, and the factors that are crucial in supporting the well-being and aspirations of people with autism.

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