

Preparing autistic young people for adulthood in Greater Manchester – Transition Guidance

This guide should be used in conjunction with the Greater Manchester Transition Checklist

1. What is autism?

Autism is a lifelong developmental disability that affects how people perceive the world and interact with others. It can be a hidden disability.

Autistic people see, hear and feel the world differently to other people. If you are autistic, you are autistic for life; autism is not an illness or disease and cannot be 'cured'. Often people feel being autistic is a fundamental aspect of their identity.

Autism is a spectrum condition. All autistic people share certain difficulties, but being autistic will affect them in different ways. Some autistic people also have learning disabilities and other conditions, meaning people need different levels of support. With the right sort of support, all can be helped to live a fulfilling life of their own choosing. Autism is neither a learning disability or a mental health problem, although mental health problems can be more common among people with autism and it is estimated that one in three of adults with a learning disability also have autism.

The estimated global prevalence of autism is 1.04%, equivalent to 700,000 autistic people in the UK. Recent UK estimates suggest that the diagnosis of autism in children is around 1.6%.^{i ii iii iv}

2. Why do we need this guide?

Improving outcomes for autistic adults is a key objective for the government. Research has shown that autistic people are not realising their full potential in adulthood in terms of employment, independent living and leading fulfilling social lives. According to the National Autistic Society's Autism Employment Gap report^v, the proportion of autistic people in full-time work is 16%, with a further 16% in part-time work. Being able to work provides people with self-esteem, money and independence, therefore it is important to plan early for future work opportunities.

Autistic people have areas of difference relating to 'communication and interaction' and 'social understanding'; they may have difficulty imagining a future they have yet to experience. Therefore, schools, colleges and services need to prepare autistic young people in planning for their future. Professionals' understanding of autism is crucial, a report by the All Party Parliamentary Group on Autism (APPGA)^{vi} found that young people were assessed for future

placements on too narrow a basis – for example, taking into account only their intellectual ability, and failing to understand the impact that being on the autism spectrum might have on an individual’s ability to manage the other elements.

Transition to adult services is most likely to be successful if planning begins early and fully involves the young person and their family^{vii}. Transition is a period of significant change and for that reason presents particular challenges for autistic young people. A good transition requires careful planning with a multi-agency approach supported by skilled people to enable children and young people to communicate their needs and aspirations.

3. Who is this guide for?

- Autistic children and young people aged 12-25 and their parents/carers
- Primarily for children and young people who have a diagnosis of autism but do not have an EHC plan
- An additional tool for autistic children and young people who have an Education Health Care Plan (EHC)
- Professionals supporting autistic children and young people through periods of transition

4. Preparation for Adulthood

The Children and Families Act 2014, and associated Code of Practice, aims to ensure that children and young people with disabilities achieve well, have choice and control over their support and are enabled to progress from education into happy and fulfilling lives. The Code of Practice (2014), Chapter 8, states ‘High aspirations are crucial to success – discussions about longer term goals should start early and ideally well before Year 9 (age 13-14) at school.’ There should be a focus on the young person’s aspirations and on the following outcomes:

- Further/higher education and/or employment – exploring different employment options, such as support for becoming self-employed and help from supported employment agencies
- Independent living - young people having choice, freedom and control over their lives, their support, and their accommodation and living arrangements, including supported living
- Participating in society - having friends and supportive relationships, and participating in and contributing to the local community.
- Being as healthy as possible in adult life.

Local authorities have a statutory duty to develop and publish a Local Offer which provides clear, comprehensive, accessible and up-to-date information about the available provision and how to access it.

Multi-agency support for transition to adulthood should take place before a young person is 18 years; however this might not always be the case. If the autistic young person is in education, this transition guide and check list can be a useful tool to influence a positive outcome in adulthood up to the age of 25 years.

5. Gaining Views

Involving young people meaningfully in making decisions about their future is key to successful transition. Consulting autistic people should be a continual process so that any adjustments can be made to teaching, support or the environment. However, there is no 'one way' of gathering views which will suit all autistic young people. Some autistic people may find it difficult to use language to effectively express their feelings or desires, they may not be able to talk about or communicate a preference for an activity unless they have experienced it themselves.

Most autistic people will benefit from having abstract concepts presented concretely so they can refer back to it e.g. by using photos, symbols or written lists. Young people may choose to communicate their views through graphic art or technology such as mobile phones e.g. by recording their voice or making a film. Creating a pupil profile or passport that contains key information about the young person should be done collaboratively between caregivers, staff and the young person. The passport should give clear, concise information about the person they are representing, including strengths, communication preferences and strategies that work.

Autistic pupils can feel isolated in mainstream schools, they need space to relax and socialise with similar young people.^{viii} Work can be done with autistic individuals to develop their understanding of the way autism affects them, when parents and the young person consent to this, for example by individual or group work with other autistic children/young people.

Differences in the presentation and impact of autism on girls should be considered. Girls may be underdiagnosed or diagnosed later in life as diagnostic criteria has typically been derived from observing autistic males. As a result girls in educational settings can be carrying an overwhelming level of unseen anxiety^{ix}, transition being one of the trigger points. Settings should promote understanding of autism amongst the student group and encourage autistic young people to support their peers through periods of transition.

As young people develop, and increasingly form their own views, they should be involved more and more in decisions about their own future. After compulsory school age (the end of the academic year in which they turn 16) the right to make requests and decisions under the Children and Families Act 2014 applies to them directly, rather than their parents. Parents and or other family members can continue to support the young person in making decisions, or act on their behalf, provided that the young person is happy for them to do so. (SEND Code of Practice 2015 – Chapter 8)

AET School and Post-16 Standards^x (The Individual

6. Person Centred Planning

Person Centred Planning (PCP) refers to the process of life planning for the individual. Many autistic people have difficulty understanding abstract concepts such as ‘in the future’, ‘when you’re an adult’. Person Centred Plans can help to make these concepts more concrete. The concept of ‘growing up’ and ‘moving on’ can be helped by using photos of them at different ages with corresponding lists of skills mastered. A PCP workbook might enable an individual to compile a document over time. It may include photos, drawings, written text or symbols.

Developing a map or path in a visual format will assist the individual to understand the concept of growing up, moving on, and gaining new skills. Using a PATH is a tool which begins where a person would like to be in the future, then works backwards in order to identify what steps need to be taken in order to achieve the desired outcome. Resources to support transition planning can be found on the Helen Sanderson Associates website.^{xi}

Transition Points

Year 7	Review adjustment to secondary environment, implement any reasonable adjustments. Develop a one page profile with the young person and family. Share information with teachers.
Year 8	Evidence progress, both academic and non-academic. If there are concerns, review strategies, gather evidence for review meetings or for statutory assessment if no EHCP in place.
Year 9	The school should aim to help children explore their aspirations and how different post-16 education options may help them fulfil these aspirations. Use strengths and interests to inform choices
Year 10	The child and their family should be supported to explore more specific courses or places to study (e.g. through taster days and visits) so that provisional plans can be prepared.

	Arrange meaningful work placements linked to young person’s aspirations.
Year 11	Support the young person and their family to firm up their plans for their post-16 options and familiarise themselves with the expected new setting. This should include contingency planning and the child and their family should know what to do if plans change e.g. due to poor exam results. Decision making can be one of the most difficult areas of the transition process and young people and their families need to be aware of all the options. There may be a variety of services available in their local area as well as possible preferred specialist services (such as autism specific residential colleges or homes) that should all be explored and viewed as part of the process. At least 3 services need to be viewed in order to make a well informed decision.
Post-16 upwards	FE colleges should plan a curriculum with pathways to prepare young autistic people for adult life by developing skills in relation to employment, independent living, health and community participation. Proposed next setting willing to be flexible and make adjustments to methods of assessment, equipment and/or the environment Young person and families provided with up to date information about adult services including the named autism lead in their Local Authority Planned access to supported internships, employment, meaningful daytime activities University visits planned, seek advice about access to personalised support on campus Living arrangements reviewed, explore Care Act assessment

7. Working in Partnership

Health workers, social workers and education providers should encourage high aspirations right from the start. They should seek to understand the interests, strengths and motivations of children and young people and use this as a basis for planning support around them. (SEND Code of Practice - Chapter 8).

7.1 Involving Families/Carers

Higher levels of parental stress are more likely for parents and carers of autistic children and young people; this can negatively affect their own well-being and ability to engage and communicate with staff. Parents should be acknowledged both as experts about their children and as a key point of continuity. They should be actively involved and supported in planning their child’s future; informed about when the transitions process has begun and each step of the planning process, and invited to and involved in reviews.

Parents and carers of autistic children and young people should be signposted to helpful local services such as those set out in the authority's Local Offer and to parent autism support groups. The Local Offer sets out in one place information about provision the local authority expects to be available across education, health and social care for children and young people in their area who have special educational needs or are disabled, including those without an EHC plan.

Cultural and linguistic diversity and minority populations are underrepresented and there are gaps in understanding how different cultures and beliefs influence the unique educational needs of autistic pupils from diverse backgrounds. Their families are also likely to find it more difficult to access the information, help and resources they need and to navigate the education system.

7.2 Education

Having an Autism Champion/Lead Practitioner in the setting is good practice, this is a key person who can provide general information about autism and specific information about individual support. All staff should be trained in autism approaches including the use of signs, symbols and visual strategies to enhance understanding and promote communication. A transition team, comprising staff from the previous and present setting, parents/carers and any therapists involved will provide consistent support for autistic individuals.

Curriculums should be adapted to provide opportunities for individuals to learn life skills and self-management techniques alongside academic skills. Schools and colleges should work in partnership to provide taster courses and linked visits to enable autistic young people to experience the environment and study programmes. Peer support can be helpful to reduce isolation and anxieties within the busy school environment.

If the young person is moving on to higher education, the young person and their family should be provided with information about support such as the The Disabled Students' Allowance and what sort of adjustments can be made at Higher Education Institutions

The Autism Education Trust (AET) school and post-16 standards and competencies are a useful framework to evidence good autism practice^{xii}.

7.3 Careers Services

The statutory framework requires every school to secure independent careers guidance for all year 8 to 13 pupils. This makes sure that all pupils have access to external sources of information on the full range of education and training options. The National Careers Service in England is the publicly funded careers service for adults and young people provides access to professional, independent careers advice through an on-line and telephone offer. The offer is available to everyone aged 13 and above with a face to face offer for adults aged 19 and above (or 18 and above if out of work and on benefits).

The service provides information about:

- what is available in terms of studying full-time at school, college or with a training provider
- support packages available to help autistic young people to access education and employment: apprenticeships, traineeships, internships

Schools and FE colleges have a statutory duty to provide access to a range of providers to inform pupils about technical education qualifications or apprenticeships and to publish information about the careers programme on their website.

7.4 Health

The Think Autism strategy, 2014^{xiii} states that Local Areas must follow statutory duties around transition for children with SEN, which will include most young people with autism. Protocols should be in place in every area for the transition of clinical mental health care for children with autism in receipt of support from Healthy Young Minds (formerly CAMHS). A child should not be discharged from children's health services until their care has been transferred to adult health services.

Young autistic people may be a particularly vulnerable group when it comes to mental health, a study by Laura Crane^{xiv} reported that young autistic people find it difficult to evaluate their mental health. A group of autistic young people developed the Know Your Normal toolkit, which may help some autistic people identify and communicate changes in their health and well-being^{xv}.

The NHS Long Term Plan, 2019 is committed to reducing health inequalities; annual health checks are currently being developed for autistic people to increase detection of health conditions and there is a commitment to increasing community based support.

7.5 Social Care

The young person should be offered support with health and wellbeing, including emotional health. National Institute for Health and Care Excellence (NICE) guidelines^{xvi} recommend discussing the transition with the young person's parents or carers to understand their expectations about transition. This should include:

- recognising that the young person's preferences about their parents' involvement may be different and should be respected
- taking into account the young person's capacity, following the principles of the Mental Capacity Act and other relevant legislation, as necessary.

The Care Act 2014^{xvii} has a similar focus to the Children and Families Act on person-centred practice and outcomes and the importance of putting people in control of their care and support. Where young people aged 18 or over continue to have EHC plans and receive support from adult social care, this will be provided under the Care Act.

Families should be provided with information about applying for a needs assessment under the Care Act. Anyone with a diagnosis of autism is eligible for an assessment by the Local Authority. Consideration should be given to the following points from the Care Act:

- Local Authorities have a legal duty to assess and prepare care plans for any one likely to be needing transfer to adult social care
- Included in that is whether the person is “likely” to have care support needs
- If the Local Authority refuses they have to give reasons for the decision.

If a request for an assessment is to be made, this is usually made to the Transitions Team in Adult Social Care and should be requested well before the young person's 18th birthday.

References

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ⁱⁱ Brugha, T. et al. (2012). Estimating the Prevalence of Autism Spectrum Conditions in Adults.

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- ⁱⁱⁱ POSTNOTE (UK Parliament Post) no 612 January 2020 Autism, study of a whole country population.
- ^{iv} Taylor, B. et al. (2013). Prevalence and incidence rates of autism in the UK: time trend from 2004–2010 in children aged 8 years. *BMJ Open*, Vol 3, e003219.
- ^v The Autism Employment Gap, National Autistic Society, 2016
- ^{vi} The All-Party Parliamentary Group on Autism 2009, Inquiry into transition to adulthood from young people on the autistic spectrum
- ^{vii} Hendricks and Wehman, Transition From School to Adulthood for Youth With Autism Spectrum Disorders: Review and Recommendations 2009, <https://www.researchgate.net/publication/258137255>
- ^{viii} 'I felt closed in and like I couldn't breathe': A qualitative study exploring the mainstream educational experiences of autistic young people, Craig Goodall 2018
- ^{ix} Girls and Autism: Flying Under the Radar, A quick guide to supporting girls with autism spectrum conditions, 2016, NASEN
- ^x Autism Education Trust school & post-16 programme, standards and competencies 2016
- ^{xi} <http://helensandersonassociates.co.uk/person-centred-practice/person-centred-thinking-tools/>
- ^{xii} <https://www.autismeducationtrust.org.uk/>
- ^{xiii} Think Autism Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update 2014
- ^{xiv} Crane, L. et al. (2019). 'Something needs to change': Mental health experiences of young autistic adults in England. *Autism*, Vol 23, 477–493. 168
- ^{xv} <https://www.ambitiousaboutautism.org.uk/what-we-do/youth-participation/youth-led-toolkits/know-your-normal>
- ^{xvi} NICE Guidelines 2016 Transition from children's to adults' services for young people using health or social care services 1.2.20
- ^{xvii} The Care Act 2014 <https://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>

Further Links:

Autism Education Trust: <https://www.autismeducationtrust.org.uk/> free downloads of Autism Standards, Progression Framework, Competencies
Preparing For Adulthood: <https://www.preparingforadulthood.org.uk/> free downloads of Independent Living, EHC planning resources etc.
National Autistic Society: <https://www.autism.org.uk/> Making Decisions guides for young people and parents

