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Autism: Improving access to social care for adults



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Introduction

This guide helps people in the health and social care sector who work with adults with autism to increase their awareness, knowledge and understanding. Autism is a lifelong developmental disorder, referred to as a 'spectrum condition' since some people with autism have profound difficulties and require specialist support, while others live largely independent lives

Please note that throughout this guide, we refer to the condition as autism, rather than as autistic spectrum condition (ASC) or autistic spectrum disorder (ASD).

Key messages

- All major pieces of social care, health and equality legislation apply to people with autism, but have not been used with sufficient consistency to support them in practice.
- Training of social care staff is key to their recognition and understanding of autism.

Diagnosis

- Social care staff have a key role to play in identifying people who may have autism, though actual diagnosis is a task for trained professionals.
- A diagnosis does not automatically lead to service provision, but has important benefits, including greater understanding of the condition and what it means, an assessment of need and improved support.
- When a person receives a diagnosis, strong links between health and social care are indispensable.

Information

- People need knowledgeable, prompt information about autism, and about where they can seek support.
- Making contact with social services for the first time can be difficult for autistic people.

Assessment

- If you are conducting an assessment always be sure to give the person sufficient notice, be punctual, be flexible and accept that some people with autism can only manage short conversations, so more than one meeting may be needed.
- Consider sensory issues both during assessment and in relation to need; other learning difficulties or conditions; sleep issues; dietary issues; carer stress and potential for a carer's assessment; and the needs of siblings and other family members.
- A carer's assessment is the vital first step in a carer accessing the support they need, yet too few carers for people with autism have received one.

Commissioning

- Commissioners should ensure there are options for autistic people in terms of where to live and who supports them, specialist services are available for those who need them, and effective joint working exists between services.

- Commissioners should involve people with autism, their families and carers in service design and delivery, and explicitly include autism in key documents.
- Commissioners should provide specialist provision for people with complex needs, supported by well-trained and motivated staff.

Support

- Frontline staff should endeavour to build good relationships with people with autism by being patient, sensitive, straightforward, consistent, calm, reliable and accepting of the person.
- Transitions should fully involve young people and their families and carers and respect their preferences.
- Developing capacity for low-level early intervention services could lessen the lengthy battles for support that many people with autism and their families have had to wage.
- People with autism are likely to benefit from managed forms of personalised budgets.

Requirements for effective service delivery

- Care Act 2014 guidance stresses the importance of those assessing the social care needs of a person with autism having sufficient training and experience to do so.
- Assessments must ensure any underlying support needs related to a person's autism are considered strongly. This is part of the Care Act 2014's priority to ensure that people's wellbeing is reflected in the assessment.
- The Care Act 2014 requires local authorities in England to consider the strengths and capabilities of those being assessed.
- 'Fulfilling and rewarding lives' sets out seven quality outcome measures against which local areas in England can test how well they are meeting the aims of the Autism Strategy.
- In England, transition planning is addressed within a young person's education, health and care (EHC) plan, covering social care, education, health and support into employment, which runs until a person is 25 (for those in education or training – excepting university study).
- In Northern Ireland, transition planning is guided by the Education (Northern Ireland) Order 1996 as amended by the Special Educational Needs and Disability (Northern Ireland) Order 2005.
- The Care Act 2014 breaks preventative services into primary, secondary and tertiary categories, going from the promotion of more general services which may be purchased by the carer or autistic person, to more focused interventions aimed specifically at particular groups.
- Policy in England calls for universal offers of advice and support in finding appropriate assistance, so personalisation should have something to offer even to those people with autism who do not have eligible needs after assessment.
- Care Act 2014 guidance gives carers equal status in relation to eligibility for assessment of support needs. In Northern Ireland, carers who provide a substantial amount of care on a regular basis for someone with autism have the right to a needs assessment when requested.

Autism: the main issues

People with autism sometimes describe the way they experience the world as a mass of people, places and events which they struggle to make sense of, and which can cause them considerable anxiety.[1] The spectrum nature of the condition has led to the expression 'if you have met one person who has autism, you have simply met one person who has autism'.[2] Some people with autism also have a learning disability.

How is autism described?

When a person receives a diagnosis, they may be told they have a particular kind of autism. People without a learning difficulty are sometimes diagnosed as having 'high-functioning autism', or 'Asperger syndrome', or 'Asperger's'. Others may be given a diagnosis of 'classic' autism, atypical autism or PDD-NOS (pervasive developmental disorder – not otherwise specified). While the need for specific names for different kinds of autism has been questioned, it is important that the preferences of the autistic person are borne in mind, such as retaining the use of 'Asperger syndrome' as a descriptor. What is key is focusing on the individual, since within each diagnostic label there may be a wide variance in the support needed for day-to-day living between different people.

A recent study [3] asked people on the autistic spectrum, parents, family and friends, as well as professionals, about the terminology they preferred to use. It found that there were many differences and strong arguments put forward for each of them. Many autistic people and parents argued that as a descriptive term 'autistic' should come first, to show that it is not derogatory: you wouldn't call a beautiful person a 'person with beauty'. Professionals preferred the 'person-first' approach: 'person with autism'. This guide uses both, acknowledging that while autism is a form of neurodiversity and may be an important part of a person's identity, it can also mean that people need support for day-to-day living. This use of terminology is also reflected in changes to the language in statutory guidance.[4]

Three areas of difficulty

Autism is experienced differently by individuals, but there are three areas of difficulty which are commonly used to describe the condition, and are also used in the criteria when diagnosing autism. These are known as the 'triad of impairments'. While people may experience different degrees of impairment for each part of the triad, people with autism experience the following:

- difficulties with social interaction – finding it hard to understand, communicate and recognise how other people are feeling.
- difficulties with social communication – struggling with verbal and non-verbal language
- difficulties with social imagination – finding it hard to imagine what others are thinking or alternatives to their own routines.

As a result, people with autism typically struggle with the rules of social engagement, such as when to speak, when to laugh and when to empathise. While many people with autism have good language skills, others will speak little or not at all, though this does

not mean they cannot communicate in other ways. Autistic people typically prefer communication to be simple and clear.

Many autistic people also have the following.

- Sensory sensitivity – over- or under-sensitivity to things such as light, sound, touch and heat, or certain tastes, textures or smells.
- Problems with motor skills, proprioception or balance.
- A need for structure – imposing their own routines in order to help make sense of the world and alleviate anxiety; such routines can sometimes become obsessive behaviours and rituals.
- narrow interests – a very close interest in a particular topic or pastime, often becoming extremely knowledgeable in it.
- A focus on detail – this is also a strength which can enable high levels of achievement in certain fields. However, it can also inhibit understanding of the ‘bigger picture’ in relationships and contexts.
- Mild difficulties in one area of the triad and severe difficulties in another.
- Skills and needs that fluctuate from day to day and moment to moment.
- Learned strategies which mask their difficulties, or carers who help to mediate difficulties so well that they are not initially apparent to a professional assessing them.

It is important to note that impairment in the area of ‘social imagination’ does not mean that people with autism lack imagination and creative talent. The spectrum nature of the condition and the idiosyncrasy of some people’s needs mean it is imperative that service providers and practitioners do not over-generalise. This also makes providing services to groups of people with autism a challenge. A key theme of this guide is the need to understand autism, but also to get to know the person with autism really well, and work with them to individualise their support based on that knowledge.

Who has autism?

Estimates of the number of people in the UK with autism vary, however the National Autistic Society and the Department of Health[5] state that about 700,000 people, just over 1.1 per cent of the population, are on the autistic spectrum. Between 20 and 33 per cent of adults with learning disabilities known to councils with adult social services responsibilities also have autism, totalling 35,000–58,000 people across England.[6] This figure excludes the many people with autism who do not use social services, often because they are unable to obtain them. A King’s College London study [7] estimated that the cost of autism in adults is £25.5 billion per year. It is often stated that there is a difference in diagnosis rates between genders, and it is generally acknowledged that more males than females receive a diagnosis, though the ratios given for this vary from study to study.[8] Concern has been expressed [9] that the new criteria for diagnosis in the ‘Diagnostic and statistical manual of mental disorders 5’ (DSM-5) makes it more

likely that women and girls may not be diagnosed, as their autism is sometimes expressed in different ways to men and boys.

While the prevalence of autism appears to be increasing, this is largely attributable to a better understanding of the autistic spectrum and the nature of the condition among referrers and those – such as psychiatrists and clinical psychologists – who carry out diagnoses.

Barriers to autism services

A perplexing juxtaposition of ability and disability and an absence of usual development alongside the presence of the unusual ... is the cause of much misunderstanding of the nature of [autism], affecting decisions about help and support.[10]

Fundamental barriers exist for people with autism in engaging with the world around them, where other people communicate in confusing or upsetting ways, adding to what many describe as ‘an ever-present sense of anxiety’.[11] A study in Sweden [12] demonstrated that the autistic people were more stressed and found it harder to cope than their neurotypical counterparts (‘neurotypical’ is used by many people with autism to describe those without the condition). Everyday places such as supermarkets, streets and hospitals can be forbiddingly noisy or unpredictable. It is not a world designed by or for autistic people.

Our work into the particular obstacles to accessing social care showed that for many people with autism, and their families and friends, it is a wearying battle to get the care they need.[13] Difficulties can be even greater for autistic people who display behaviour that challenges services, or who have needs that cross the boundaries of several different services. Individual professionals may be extremely helpful, but the system itself is seen as ill-informed, complex and set up in ways that exclude or alienate people with autism.[14]

Barriers to receiving services include:

- A lack of awareness about autism and understanding of how it might affect each autistic person differently, from some social care staff, other professions and society generally.
- The ‘invisibility’ of autism as a condition. People with autism do not have obvious physical signs of it, and are sometimes therefore thought to interact in ways that are simply odd, ill-mannered or alarming.
- Disability and benefits legislation and assessments, which sometimes seem shaped by a perception that a disability must have a physical manifestation. Receiving support can rely heavily on good social communication and social interaction skills when completing forms or taking part in assessments.
- The degree to which some people with autism can be talented and, particularly if they have no learning disability, very articulate. This can lead professionals to assume that they do not need social care or support.

- The blocking of people with high-functioning autism or Asperger syndrome from some social care services, because they do not qualify for learning disability- or mental health-specific services.
- Many services, such as drug and alcohol, not feeling confident in offering a service and trying to refer people with autism to specialised services that are scarce, and can be geographically or financially difficult to access.
- Many social services introducing generic teams, which have separate sections for initial assessment and for ongoing care.

Social care assessors sometimes lack sufficient awareness of autism to do the job of establishing the needs of people with autism properly.[16] The paperwork used – assessment forms, or resource allocation systems in England – can be too blunt to pick up the complex needs that people with autism sometimes have. They can also rely on good communication skills, and the insight, willingness and confidence to disclose personal details.

Sometimes needs can be met creatively and flexibly, and in ways that are not expensive, however some people with autism have really complex needs and meeting them can involve skilled staff or intensive support. This can be costly, and underfunded care packages are another barrier to a good quality of life for some.[17] This is a concern at a time when councils and clinical commissioning groups (CCGs) are having to reduce what they spend.

The national Autism Strategy for England was launched with the Autism Act 2009, and the ‘Fulfilling and rewarding lives’ strategy which followed [18] and its update, ‘Think autism’ [19] are aimed at addressing some of these barriers.

‘Think autism’

‘Think autism’[19] sets out to update the government’s strategy for improving outcomes for adults with autism in England, first set out in ‘Fulfilling and rewarding lives’ [18] which called for a societal culture shift, so that the equality and human rights of autistic people are respected. To help improve the quality of life for people with autism, ‘Fulfilling and rewarding lives’ set out the need for better:

- autism awareness training
- access to a diagnosis
- assessments of people with autism
- service and support
- local leadership and planning – including a lead commissioner for autism.

The strategy also sets out the costs for people with autism of not changing things:

- continued poor physical and mental health
- continued involvement in crime and substance misuse
- continued benefits dependency

- continued economic and emotional costs for their carers and families.

The strategy provides a clear narrative:

- to raise awareness among professionals
- to train those who play key roles in the lives of people with autism
- to make sure diagnostic services are available
- to ensure transitions into adult services are managed successfully
- to ensure that good planning and leadership are in place so that quality local services can be provided.

'Think autism' retains these commitments and builds on them, setting out its key aims to:

- increase awareness and understanding of autism
- develop clear, consistent pathways for the diagnosis of autism
- improve access for adults with autism to services and support
- help adults with autism into work
- enable local partners to develop relevant services.

'Think autism' outlines 15 'priority challenges' established through a consultation with autistic people, families, carers and professionals. Outlined in the next section, these are divided into three parts related to:

- being recognised as an equal within local communities
- getting the right support across the lifespan
- developing skills, independence and working life.

'Think autism' is backed by statutory guidance.^[20] This incorporates changes which draw on the duties written into the Care Act 2014 as well as expanding on previous guidance from 2010.^[21] It expands on the responsibilities of local authorities and the NHS, for example, giving guidance on the different levels of training people might need to understand autism. It provides guidance on five further areas where improvements should be made, setting out some examples of successful practice:

- preventative support and safeguarding
- reasonable adjustments and equality
- supporting people with autism and complex needs
- employment
- criminal justice.

The strategy and guidance call on public bodies to meet their existing duties to people with autism. All major pieces of social care, health and equality legislation apply to people with autism, but have not been used with sufficient consistency to support them in practice. The strategy and guidance make it clear that this is not acceptable and call for a better use of existing law to support people with autism.

Importantly, the strategy and guidance state that a diagnosis of any autistic spectrum condition, including Asperger syndrome or high-functioning autism, is a reason to assess somebody for services.[20] While this does not guarantee services will be provided, the move to ensure assessment is carried out appropriately and proportionately [22] and the Care Act's focus on outcomes-based eligibility should help to ensure that assessment looks at the person rather than their diagnosis.

As well as aiming to improve public services for people with autism, the documents call for all mainstream services – such as transport, leisure, employment and the police – to get better at adjusting to, and meeting the needs of, people with autism. The statutory guidance [20] also states that local authorities will need to keep and provide data about autism in their area, including:

- the numbers of autistic people known
- the range of need for support to live independently
- the age profile of people with autism.

The guidance allows for local discretion in how the strategy is implemented, however health and wellbeing boards, formed through the Health and Social Care Act 2012, are expected to play a part in planning local services. Concerns remain that a lack of funds and central direction may hamper some of the key aims such training and diagnosis.[4,14] Nonetheless, local authorities, and most NHS bodies, will need to abide by the guidance.

While progress has been made since the Autism Act 2009 there is still much to be done to show as a society that autistic people have the same rights to life and independence as other people.[23,24] Where guidance is followed, this can lead to real improvements in the day-to-day lives of autistic people, as well as carers and professionals.[16]

The 15 priority challenges

The priority challenges are taken directly from 'Think autism',[19] and used to frame the statutory guidance issued in 2015 for practitioners in England and Wales.[20]

An equal part of my local community

- I want to be accepted as who I am within my local community. I want people and organisations in my community to have opportunities to raise their awareness and acceptance of autism.
- I want my views and aspirations to be taken into account when decisions are made in my local area. I want to know whether my local area is doing as well as others.
- I want to know how to connect with other people. I want to be able to find local autism peer groups, family groups and low-level support.
- I want the everyday services that I come into contact with to know how to make reasonable adjustments to include me and accept me as I am. I want the staff who work in them to be aware and accepting of autism.

- I want to be safe in my community and free from the risk of discrimination, hate crime and abuse.
- I want to be seen as me and for my gender, sexual orientation and race to be taken into account.

The right support at the right time during my lifetime

- I want a timely diagnosis from a trained professional. I want relevant information and support throughout the diagnostic process.
- I want autism to be included in local strategic needs assessments so that person-centred local health, care and support services, based on good information about local needs, are available for people with autism.
- I want staff in health and social care services to understand that I have autism and how this affects me.
- I want to know that my family can get help and support when they need it.
- I want services and commissioners to understand how my autism affects me differently through my life. I want to be supported through big life changes such as transition from school, getting older or when a person close to me dies.
- I want people to recognise my autism and adapt the support they give me if I have additional needs such as a mental health problem, a learning disability or if I sometimes communicate through behaviours which others may find challenging.
- If I break the law, I want the criminal justice system to think about autism and to know how to work well with other services.

Developing my skills and independence and working to the best of my ability

- I want the same opportunities as everyone else to enhance my skills, to be empowered by services and to be as independent as possible.
- I want support to get a job and support from my employer to help me keep it.

Further reading

- [‘Think Autism: fulfilling and rewarding lives, the strategy for adults with autism in England: an update’](#) (2014), London: Department of Health.
- [‘Care and support statutory guidance’](#) (2016), London: Department of Health.
- [‘Statutory guidance for local authorities and NHS organisations to support implementation of the adult autism strategy’](#) (2015), London: Department of Health.

The policy context in Northern Ireland

In Northern Ireland, a separate set of developments have taken place in response to the needs of people with autism. An independent review of autism services was undertaken during 2007 and its recommendations resulted in additional resources being secured by the Department of Health, Social Services and Public Safety (DHSSPS) to develop health and social care provision for autism. The 'Autistic spectrum disorder (ASD) strategic action plan 2008/09–2010/11'[25] was also informed by other reviews such as the Bamford 'Autistic spectrum disorders' recommendations [26] and 'Families matter: supporting families in Northern Ireland'.[27] It was updated in 2013.[28]

The plan highlights the need for a person-centred and whole-life approach to effective provision of health and social care services, which includes the statutory, private, voluntary and community sectors. It is linked to a care pathway approach.

Five key themes

The initial action plan was organised around five key themes:

- service redesign to improve autism care
- performance improvement of autism services
- training and raising awareness
- improving communication and information for individuals and families
- effective engagement and partnership working.

The Autism Act (Northern Ireland) 2011, implemented in May 2011, covered two areas for development. First, it required changes to the Disability Discrimination Act 1995 to include people with autism, making it clear that 'a condition which has a substantial and long-term adverse effect on someone's ability to take part in normal social interaction or in forming social relationships can constitute a disability',[29] thereby promoting access to services and benefits. Second, the Act required the Northern Ireland government to implement a cross-departmental Autism Strategy which outlines how the health, educational and social needs of people with autism will be addressed across the lifespan. It must also set out how families' and carers' needs will be addressed, and develop an autism awareness campaign.

A multi-disciplinary Regional Autistic Spectrum Disorder Network (RASDN) was set up to take the plan forward, and began work in April 2009. It is linked to the broader implementation of 'Delivering the Bamford vision'.[30] Autism sub-groups have been established to take forward a range of work streams, and developments will be informed by the evidence base of good practice for diagnosis, assessment and service provision.

The autism adult care pathway sets out the guidance needed to deliver services to adults with autism across Northern Ireland [31] through the Regional Autistic Spectrum Disorder Network, made up of a wide range of stakeholders.

Update to strategy

An update to the Autism Strategy, with a second action plan, was put in place in 2013,[32] and sets out 11 themes broken down further into strategic priorities. The action plan is across the lifespan and this is reflected in the wide-ranging themes:

- awareness
- accessibility
- children, young people and family
- health and wellbeing
- education
- transitions
- employability
- independence, choice and control
- access to justice
- being part of the community
- participation and active citizenship.

Further work by the health and social care trusts in Northern Ireland is ongoing to develop services for people with autism. This is supported at a strategic level by commissioning arrangements, with guidance issued by the Health and Social Care Board.

Further reading

- [‘The Autism Strategy \(2013–2020\) and action plan \(2013–2016\)’](#) (2015), Northern Ireland Executive.
- [‘Autism adult care pathway – Regional Autistic Spectrum Disorder Network \(RASDN\)’](#) (2013), Health and Social Care Board.

Awareness-raising and diagnosis of autism

Social care workers and autism

Running through recent government publications about autism, and mirrored in our research, is the view that social care staff, among others, do not know enough about autism to identify when someone may have it, or to properly support someone who does. The 'Think autism' guidance sets out to ensure that better understanding and awareness is put in place for social care services.[20]

As long as they realise that in a way it's like teaching someone who's blind to see, or someone who's deaf to hear. There has to be real understanding that our brains are differently designed so we really can't spot body language fast enough, etc.

(Autistic adult)[33]

If there is one thing people with ASD want and need, it is greater awareness. We want people to understand us and to accept us as we are. We do not want cures or medical interventions, just understanding.

(Autistic adult)[13]

Training content

Many people need to understand autism better: employers, benefits workers, people in the criminal justice system, housing officers and health professionals. People with autism also need social care to work better for them, so it is vital that staff become more knowledgeable about what autism is, and the needs of people who have it.

Training should:

- cover how to recognise autism and its diversity, and how to make reasonable adjustments to accommodate people with autism
- be delivered efficiently – e.g. sharing training between organisations, or including autism in general equalities training
- be delivered in detail for those conducting assessments, those working directly with people with autism, and the managers of these people [16,19,20]
- alter behaviour and practice among key professionals – it isn't enough to attend training but then carry on as before
- be ongoing, as thinking about autism continue to develop
- include input from people with autism and their families [4,21]
- cover awareness-raising about Asperger syndrome and high-functioning autism – the lack of support offered to people with autism of these types means that staff may have less awareness and experience.[11,13]

Training delivery

Local areas should set out plans for how key staff will be trained. Training must be available to personal assistants and others working in micro-commissioned support services. Commissioners should insist that good autism training is built into the services they purchase, and regularly updated. One aspect of awareness-raising is that of 'mutual misunderstanding'. [13] People without autism can lack understanding of the condition which can make communication hard, but people with autism can find the language and customs of the neurotypical world perplexing and anxiety-provoking, to the extent that they give up trying to access services. While some people with autism have called for training in how to understand the neurotypical world,[34] for there to be a meeting of minds, it is up to those who do not have impaired social communication to make more adjustments.[11]

Making these adjustments, and spreading awareness about autism, is vital in ensuring that people are directed to the right sources of support.

Diagnosis of autism

At the beginning you just think 'ah, the diagnosis is there I'll just automatically get services', but that's the very, very beginning ... you're not always given a lot of information about what that diagnosis actually means.

(Mother of autistic man)[13]

Autism diagnosis is a task for trained medical professionals – however, a well-informed social care workforce has a vital role to play in identifying people who might have autism, but are as yet undiagnosed. Social care workers are also important sources of support at the point of diagnosis, and in the weeks and months that follow.

The benefits

Getting a diagnosis of autism, especially as an adult, can be hard, and four out of five adults in our research found it either difficult or impossible.[13] It may be particularly difficult for women, as their autism may present in ways unexpected in traditional diagnosis.[8] A diagnosis of autism does not automatically lead to service provision, but there are some key benefits:

- It helps explain what had previously been unknown or misunderstood.
- It should lead to an assessment of need by social care – in England as part of the statutory duties described in the guidance for 'Think autism'. [20]
- It can help shape an improved support package, as long as this is not done in a mechanistic, 'someone has this, they get this' way. [13]
- It avoids the problems of misdiagnosis, as faced by people with autism wrongly thought to have a mental health problem, and can help to provide a better picture of support needs where autism sits alongside another condition such as learning disability.

- It can assist with accessing services and benefits, such as a disabled students' allowance. [2]

Referral

The social care workforce needs to know how to make referrals for a diagnosis, and this must form part of the awareness-raising and training they receive. This requires good links between local health and social care bodies, so that timely, appropriate referrals can be made.

While having a diagnosis is important for people, without up-to-date training for service providers it can also lead to misconceptions about what it means to be autistic: 'At university the counsellor immediately jumped on my application form that I had put down AS [Asperger syndrome] and said that it was impossible as I didn't have a "special talent" and I was "too expressive" as I looked upset ...'. [3]

There are several important things to consider at the point of diagnosis, and in the period that follows.

- A diagnosis is a reason to assess people's social care needs, rather than exclude them from assessment. [15, 18, 19]
- Diagnoses can indicate what a person might benefit from, but should not be any more than a guide.
- There is still misunderstanding from service providers as to what a particular label means, and further training to understand autism better is needed in areas such as higher education, and the police. [19]
- Good links between health and social care are indispensable at the point when someone receives a diagnosis. We found that 77 per cent of people felt poorly served by support services at the point of diagnosis. [13]
- Social workers are trained to help support people in periods of change and crisis, and have a key role to play in making sure that people get better support when diagnosed. The guidance for 'Think autism' requires social services to carry out an assessment of needs following diagnosis. [20]
- Information-sharing between diagnostic services and local authorities/trusts, private and/or voluntary social care providers needs to be swift and appropriate.
- People need good, prompt information about autism, and about where to get support. Who provides what information will vary from area to area, but different organisations must communicate with each other.

Of course, people do not need a diagnosis of autism to be assessed for social care services. Conversely, although people should be assessed if they do have a diagnosis, having autism doesn't mean that they will then be eligible for support.

Making sure that, following diagnosis, the assessment for and provision of social care services is done in ways that work for people with autism is the subject of the next section.

Assessment, accessibility and acceptability of autism

Assessment for people with autism

When I get to see someone ... I don't always understand what they are asking me. I don't give complete answers to their questions and they don't press for additional information. I get upset and often cry, then I feel stupid and they think I'm overemotional or exaggerating my symptoms.

(Autistic person)[13]

Offering an assessment to someone who has autism is a proactive duty for local authorities [20] and health and social care trusts.[31] In the past, many adults with autism, particularly those with Asperger syndrome or high-functioning autism, did not have assessments,[37] and often those assessments that were carried out were in areas with limited training in how to assess people with autism.[38]

The new guidance for the Care Act 2014 [15] stresses the duty to have suitably-trained people conducting assessments. Because many people with autism might have other conditions, as well as physical health issues, assessments must ensure that any underlying support needs related to a person's autism are considered.[39] This is part of the Care Act 2014's priority to ensure that people's wellbeing is reflected in the assessment.[15]

Barriers

People with autism can find assessments perplexing. While this in part relates to the nature of autism, many carers also report finding assessment processes confusing, so the issue is one that services should address.[40] The Care Act 2014 states that in England people have the right to independent advocacy if they need someone to help them have their say about their care needs, though this role might be carried out by a family member or friend. The Act also states that assessments need to be carried out in a way that is appropriate for the person being assessed.[15] At this time, there is no statutory requirement in place in Northern Ireland, however access to advocacy is recognised as good practice.

Assessing someone with autism can be difficult, because people with autism:

- can lack self-awareness, the ability to express their needs and the knowledge of what constitutes a 'normal' alternative to their own lives
- may not want to engage with an assessment, or understand its purpose and connection to receiving services
- may have needs unrelated to their level of intellect, or masked by fluent language skills

- may not understand the questions, because they are asked ambiguously or unclearly – the question ‘Can you cook by yourself?’ may be answered ‘Yes’, even if the person has to be prompted at every stage of the cooking process
- may not like the attention, or the focus on their need may cause them anxiety, so their answers may reflect their desire to finish quickly
- may have been let down by services in the past
- may have spent a great deal of time and effort developing ways to cloak their difficulties
- may have family members/carers who mediate the outside world and compensate for their difficulties
- may come from cultures in which people are reluctant to acknowledge developmental disabilities.

Successful assessment

Preparing in advance and flexibility towards the person with autism may help the assessment capture the right information, and the assessment must be proportionate to the complex nature of autism.[15] If you are conducting an assessment with someone with autism:

- be clear about your role from the start
- consider sending a photograph of yourself in advance
- accept that you may need more than one or two meetings; people with autism can often only manage short conversations
- be flexible about how information is recorded; use formats that the person with autism can understand
- find out what would help the person feel in control of the meeting
- where appropriate, find out from the person’s family or carers how they best communicate
- read about the person on their file, without fixing your views on the basis of what you learn there
- ensure that you are punctual as lateness can cause anxiety
- focus on the person’s strengths and achievements.[41]

You might also want to ask yourself:[42]

- Does the person have special interests I could use to foster a good relationship?
- Does the person have sensory sensitivities; should I, for example, not wear perfume or aftershave?
- Are there things that might trigger anxiety for the person?

- Do I have to do the assessment face to face, or could it be done by email, for example?
- Can I send the assessment questions in advance so the person can prepare their responses?
- Does the person need extra time to answer questions?
- Have I been asking them questions while asking them to read something or fill out a form?
- Does the person want a friend, family member or advocate with them?
- Is there a time of day that would suit the person well?
- Would the person prefer to be assessed while walking, for example, so that eye contact need not be made so often?

While some of these examples are of specific relevance to people with autism, others are simply good practice in any social work or social care assessment.

There are also a number of issues, often connected to autism, which an assessor should consider:[\[42\]](#)

- sensory issues, both in the room at the time, but also as a factor in determining need
- other specific learning difficulties or conditions, such as dyslexia or attention deficit hyperactivity disorder
- sleep issues – many people with autism have disrupted sleep patterns, which can be difficult for them and their carers
- dietary restrictions
- stresses faced by the carer: a separate carer's assessment should be offered – see the 'Carers' section in this guide. In order to lessen anxiety for the carer, this could be offered or arranged at the same time
- the needs of siblings and other family members.

Consider risk factors that may arise from people's obsessions, dietary problems, social isolation, self-neglect, running/absconding, mental health problems, inappropriate sexual behaviour, self-harm and other factors. Consider too whether the person with autism is also a parent or carer and, if so, how their autism affects how they care for the other person.

The impact of autism should be considered when assessing under the Mental Capacity Act 2005 or the Mental Health Act 2007. For example, someone with autism may have good theoretical knowledge about an issue and appear to have capacity, but in fact are not able to retain or weigh up the information.

The Care Act 2014 requires local authorities in England to consider the strengths and capabilities of people being assessed. This approach emphasises that through building on individuals' strengths – personal, community, and in social networks – assessments

are more likely to support the outcomes that those using services want.[41] There is more about the strengths-based approach in the section on ‘Personalising services’.

For more tips on communicating generally with people with autism, see the ‘Frontline staff’ subsection.

Further reading

- ‘Social care: assessment of need for adults with an autism spectrum disorder’ (2008), National Autistic Society.
- [Care Act 2014](#) (2014), Social Care Institute for Excellence.

Accessibility and acceptability

If I were in a wheelchair no one would be asking me to take the stairs!

(Adult with autism)[13]

Here, we explore in detail some of the challenges people with autism face when trying to access social care.

Barriers

Bureaucracy and systems

Contacting social care services, particularly for the first time, can be problematic for autistic people. When offering services, information or support, it is important to bear in mind that:

- form-filling and phone calls can be perplexing and a significant obstacle to services
- face-to-face meetings may be disconcerting, as they may involve travel to unfamiliar places to meet unfamiliar people
- some autistic people will feel overloaded with sensory impacts by the time they arrive, and will struggle to focus on the task in hand – services should therefore be flexible, and support people to choose whatever works for them
- people might miss appointments and should be reached out to, not denied a service [13]
- services should continuously examine their processes and language, to identify how these might form a barrier
- people may need to build up the amount of time that they can spend with a new person or build up their trust
- people may need support to identify and ask for reasonable adjustments to services.

Much of what makes people with autism anxious and disconcerted about contact with bureaucracy – such as unhelpful telephone operators, long periods on hold, or information not being shared clearly – can also annoy the general population. Getting it

right for people with autism need not be an extra burden for organisations; it is something that they ought to be doing anyway to improve their services.

External perceptions

Some autistic people fear other people's perceptions, and feel they are not accepted, or believed when they ask for help.[13] It can be frustrating for autistic people and their families that they might be expected to do things that are simply beyond them, because there is no visible reason why they can't. Other people may stay away from services because of concerns about the stigma involved in having a label or receiving services; this can be heightened for people who put a lot of effort into appearing neurotypical or who have been bullied extensively.

Islands of accessibility

In the research study which underpins this guide, we came across many people for whom services were only accessible because a single individual undertook a key role in ensuring this would happen. The roles of these helpful people varied – a day centre worker, a GP, a social worker – but they often assisted despite the systems in which they operated, rather than being supported by those systems.[13] Turning individual islands of accessibility into something more systematic would help make things better for people with autism.

Suitability

Too many services, when they are offered, are not suitable for individuals on the autistic spectrum. Designed either for people with learning disabilities or for people with mental health problems, they lack the specialist knowledge and experience to offer effective support. Many places, for example, rely on a lot of group activities, which may not work for autistic people.

People with autism who display behaviour that challenges services, such as self-injury, aggression, damage to property or substance misuse, can find suitable services particularly difficult to access,[13] and care must be taken to ensure that they are provided with appropriate services within the community wherever possible.[20] Too often, people are placed in expensive residential or hospital provision, or spend long periods in assessment and treatment units, where they can become detached from their family and community.[43]

Commissioners of autism services

Enabling effective access to social care for people with autism involves an in-depth knowledge of what an individual needs. It is therefore difficult to set out in detail what commissioners should do for everyone with autism, but enough is known about what generally makes services accessible to people with autism to give some pointers.

Commissioners should try to ensure that:[44]

- there are local options for people with autism about where to live, how to spend their time and by whom they are supported
- specialist services are available for those who need them, offering structure, routine and continuity

- mainstream services are competent to support people with autism, with trained staff, low-arousal areas and flexible processes
- outreach provision is in place to support people with autism in their own homes
- provision reflects the need of some people with autism for predictable, reliable services
- services are flexible enough to meet fluctuating support needs that can change from day to day
- effective joint working exists between these services, and with health services.

In addition, commissioners should:

- engage people with autism and their carers in service design and delivery
- look for inconsistencies between the number of children receiving services and those receiving services as adults [20]
- explicitly include autism within key documents such as equalities policies, joint strategic needs assessments and local housing plans
- use the Equality Act 2010 requirements (or equivalent legislation) to ensure that reasonable adjustments are made to local processes and services
- ensure that there is local competence in using the Mental Capacity Act 2005 (or equivalent legislation) to support people with autism to make decisions
- make use of the 'Mental health and learning disability standard contract' (or equivalent), which explicitly covers autism (this is a legally binding document covering all NHS-commissioned services for the named client groups, and can help ensure services are meeting their obligations to people with autism).

One approach is to provide services in a local or regional centre of excellence,[45,46] a 'one-stop shop' for people with autism,[36] offering:

- training and employment support
- diagnosis services
- consultancy and advice
- outreach to prevent family breakdown
- social groups and skills training
- education
- accommodation advice
- brokerage and advocacy
- support with practical tasks, paperwork and forms.

These services may be provided through local or regional social enterprises or third-sector organisations.

The provision of good quality housing underpins many of the other things that people with autism need to enjoy a good quality of life. Again, each person with autism will have highly individualised needs, so commissioners should provide flexible options:

- specialist provision for people with highly complex needs
- good-quality residential options, considering factors such as low-arousal settings, noisy activities like vacuuming taking place when people are out, spacious, uncluttered rooms with muted tones, and fixtures and fittings that can withstand damage [42]
- good-quality supported independent living options with similar adjustments, bearing in mind some people with autism will be parents or carers, and will need sufficient space for family members
- housing options that are not 'move-on' or time-limited
- additional security measures or telecare if people are deemed vulnerable or have high levels of anxiety.

With specialist provision, regional cooperation may be needed. More locally, the focus should be on ensuring that mainstream services adapt to people with autism, including those with behaviour that challenges services, rather than excluding and marginalising them.[46,47]

People looking to provide services to black and minority ethnic people with autism, or people with autism from the lesbian, gay, bisexual and transgender (LGBT) community, will need to ensure that services can meet all the needs of the people they support.[19]

Frontline autism staff

Working with autistic people can be very different from working with other groups using services, and it is important that this is understood by frontline staff. Furthermore, teams need to work together to ensure they are supporting each other in relation to planning – for instance, by sharing information about service users' preferences in good time.[16]

Use a strengths-based approach

To ensure that services are accessible, it helps to bear certain things in mind. The most important is that a person's autism will never be more than one part of what makes them who they are, and using a strengths-based approach will be helpful.[41] In order to build good working relationships with people with autism:[42]

- be patient: autistic people can be challenging, can appear rude, and may miss appointments; checking understanding is important when the autistic person needs to process new information and vocabulary
- be sensitive and straightforward, especially in the way you communicate
- be consistent, calm and reliable; turn up on time
- be accepting of the person and their autism.

Plan in advance

Planning in advance means a person's likes can be catered for, and potential triggers identified and avoided. When planning a day, or an activity, always consider the following.

- Include the person to the maximum degree possible.
- Have a clear structure of activities in mind, but also have systems for introducing new ones. People with autism find change difficult but not impossible. It might take several attempts, though, before someone takes on a new activity.
- Avoid rigidity, and doing the same thing every day. Be understanding of a person's aversion to change, but do not get paralysed by this, or use it as an excuse for lowering your expectations of what people can achieve.[48]
- Remember that ongoing predictability of provision will be what some people with autism need.
- Prepare for meetings: discuss things with family in advance, if appropriate. Ask the person with autism if they'd like to bring something with them, perhaps from their area of particular interest, to make them feel more at ease.[49]
- Be clear about the purpose, length and likely outcomes of any activity or meeting (and, if appropriate, back up the outcomes of a meeting in writing later on).
- Be flexible, and change your approach if you're causing distress.
- Make use of special interests, and where appropriate use wall-charts or timings to provide structure,[49] or use IT systems and apps to provide prompts and reminders.
- Remember that people with autism may have comprehension that varies from day to day, hour to hour.

Communicate

Whether planning or engaged in an activity, good communication is vital.[13,50] Consider the following,[51] bearing in mind that the communication needs of individuals will vary.

- Be conscious of the environment in which you are communicating. Lights, sounds, smells, animals or crowds can all be distracting.
- Use very clear, literal language, and consider any possible alternative interpretations of what you say. Avoid metaphor, sarcasm and jokes.
- Allow the person time to process what you've said, and don't repeat it, or say something else, too quickly.
- Check for understanding on key points and concepts.

- Be consistent: across your own communication, with other staff, and between staff and the person's family and friends.
- Photographs or objects can help establish routine, lessen ambiguity and alleviate anxiety for some people, or be a way of offering choices.
- The person's comprehension might not be as good as their verbal expression. A person might just be echoing what you say, rather than answering a question.
- Facial expressions or body language are unlikely to be understood, and may be misconstrued entirely.
- The person may switch off when two other people in the room are talking to each other, even if the discussion is relevant to them.
- Sit to someone's side if they are uncomfortable with eye contact.
- Use the person's name often.
- Be calm and still, with no large gesticulations.
- Communicating well in advance of an activity will help some people mentally prepare for it. For others, it may be better to discuss something just before it's going to happen. This can help avoid unnecessary distress.
- Consider all of this, but none of it is as important as getting to know the individual.

Not all autistic people use spoken language to communicate. Several tools are used to assist the communication of people with autism, many involving visual devices. Autism apps for touch-screen tablets are available both for communication and education. PECS (picture exchange communication system) is an expressive tool which involves swapping pictures for a desired activity or object. Labelling involves attaching a symbol to the thing it represents.

Further reading

- ['Community Care for adults'](#) (2009), National Autistic Society.

Autism support strategies

There are many frameworks for supporting people with autism. Three interventions suggested as helpful by the National Autistic Society are described here. The individual and their own needs must be considered first, as different approaches may work more or less effectively for different people.

SPELL

The SPELL framework, developed by the National Autistic Society, is based around five key pillars:

- the importance of STRUCTURE in making the world predictable and manageable

- POSITIVE approaches and expectations as a way of building people's strengths
- an EMPATHY for the way a person with autism perceives their world, so that things they find positive can be focused on, and things they find distressing can be avoided
- LOW-arousal approaches, in both a sensory and interactional sense
- LINKS with families and supporters to ensure consistency and predictability in how people are supported.

SPELL also stresses the individuality of each person with autism as the basis of all interventions with them. Applying SPELL principles can support people across the autistic spectrum, and can complement other approaches such as TEACCH.

TEACCH

TEACCH stands for the Treatment and Education of Autistic and Communication-handicapped Children, and although there is an education focus, it is also used with adults. It was developed in North Carolina in the 1960s and 1970s, and now forms the basis of a range of interventions with children and adults with autism, such as diagnosis and assessment, individualised support, special education, social skills training, employment training and support to families.

The TEACCH programme aims to support people with autism to manage their home, educational and professional lives, by addressing environmental obstacles, and working with people to adapt their behaviours. There is a focus on structured learning and skill development.

Social stories and comic strip conversations

These two methods were developed by Carol Gray in the 1990s.[52] 'Social stories' explain clearly and simply what happens in social situations, for example, using a social story to help an autistic person understand what is going to happen in a medical procedure.[49] Comic strip conversations are more visual, using colour, shapes and stick figures to tell the 'story' and are sometimes used to explain in a step by step way how to do something in the social world.

There is software available for both social stories and comic strip conversations, and when working with autistic people who prefer technological means of communication these may have some advantages.

Further reading

- [Centre for the Advancement of Positive Behaviour Support](#) (2014), BILD
- ['Social stories and comic strip conversations with students with Asperger syndrome and high-functioning autism'](#) (1998), Springer.
- ['Strategies and approaches'](#), The National Autistic Society

Specialist autism services

There is an argument that if mainstream services improved their ability to meet the needs of people with autism, then specialist services wouldn't be needed. 'Think autism' [19] and its attendant guidance,[20] along with the action plan for Northern Ireland,[28] with their focus on raising awareness across services, aim to make all services better for people with autism. But there needs to be a balance, and offering mainstream services must not be done simply to reduce costs.[53]

Whether specialist services are in place will depend on local need and commissioning priorities. But the guidance [21] stresses that specialist services have a 'pivotal role' in improving outcomes for people with autism. Specialist services, especially multidisciplinary ones, do seem to hold out the promise of better outcomes,[10] and 'Think autism' continues to promote autism-specific bodies for the delivery of services, such as specialist autism teams and autism partnership boards.[20] This message is also stressed in the action plan for Northern Ireland.[28]

A National Audit Office study [35] showed that specialist teams can improve outcomes, and have the potential to save significant sums of money. For example, specialist help for supported employment for autistic adults can lead not only to long-term cost savings, but 'individual gains in social integration and well-being'. [54] It is worth noting that if no specialist autism care management team is in place, then it is for each local social services area to provide clarity as to which team will take on the support for people with autism who have no attendant learning disability or mental health problem.

Further reading

- 'At work', The National Autistic Society

Joint working in autism

The service landscape in autism

Joint working is important, because for people with autism, social care is just one part of a wider service landscape. They also need health services, housing, jobs and benefits, as well as access to mainstream services or support.

While social care can be hard to access, so too can these other service areas.[13] This can mean that some people with autism access nothing, and so miss out on the chances of cross-referral to other services. They risk, therefore, living lives that are really constrained, because they are denied access to work, vital health services, social contact and a decent place to live.

The complexity and inaccessibility of the benefits system was a major theme in our research.[13] People with autism can be anxious about applying for, and perhaps being refused, benefits. The forms involved can be forbiddingly complicated, and the office spaces that house benefits staff can be bright and noisy.[13,35] Not applying, however, can lead to financial disadvantage.

Healthcare

It can also be hard for people with autism to access healthcare, for a number of reasons:

- bright, noisy settings
- lack of awareness among health professionals
- diagnostic overshadowing – everything being put down to a person's autism
- difficulties in communicating – for example, explaining where the pain is and what it feels like [50]
- poor awareness of autism in mental health services, which tend to have a recovery focus
- some health interventions require touch, which can distress some people with autism
- hypo-sensitivities, which can make it difficult to identify if someone is in pain.

Employment

Employment, for those with autism, as for most people, can be important in developing self-esteem and promoting independence. In an English study following the implementation of the Adult Autism Strategy 2009 and the Equality Act 2010, the researchers found that barriers to employment still included a lack of reasonable adjustments and a lack of understanding about autism from employers.[55] Some key points are worth considering.

- With the right support, autistic people can make excellent employees.

- Many people with autism who are in work are employed part time, and in roles that do not reflect their qualifications.[55] This may partly be a reflection of the need for work which does not cause overload.
- People with autism find interviews difficult: the concept of selling oneself, or putting a positive gloss on one's experiences can be wholly alien to them.
- Reasonable adjustments should be made in keeping with the Equality Act 2010 (or equivalent legislation): work trials can give a more accurate picture of someone's skills than interviews, for example.
- Job descriptions needs to be considered. Many jobs, for instance, call for 'good communication skills', which can be a barrier to people with autism, when they are not actually that important.
- Many autistic people experience difficulties with the social aspects of employment, such as deciding what information to share with colleagues, or how to report difficulties such as harassment.
- Altering some of the difficulties that autistic people might experience (such as harsh lighting and noisy environments) would benefit non-autistic workers as well.[55]

Housing

Getting the right housing, and the right support that comes with it, can also be key for many people with autism. In the subsection entitled 'Commissioners', we described some of the main housing needs of people with autism. However, because many such people are not considered eligible for social care support, they often live with families, or in general needs public housing. Mainstream housing providers should therefore develop their own awareness of and competence in autism, to ensure, for example, that people with autism can access advice on paying the rent or dealing with neighbours.

Education

Universities and colleges are making some progress in catering for people with autism. The Disabled Students' Allowance, for instance, can be used to fund social as well as academic support. Many universities and colleges remain a challenge for people with autism, because of the novelty and variety of the environment,[2, 56] but quiet periods in events such as the fresher's fair and web-based courses are examples of reasonable adjustments that can be made, and there are some colleges with a focus on providing a balanced environment for people with severe autism and learning difficulties. Other potential adjustments include:

- pastoral support from trained staff
- autism awareness training
- information provided in clear and literal language, including in exams
- extra time for individual pieces of work, and for courses as a whole
- support around organising time

- scheduling supervision/classes at regular times each week
- extra support around exam time and other periods when routines change
- working in small groups where possible [56]
- making specific accommodation arrangements, taking into account sensory sensitivities.

As social care opens itself up to people with high-functioning autism and Asperger syndrome, links with the higher education sector are likely to grow as support improves.

Collaborating and joint working for autism

Social care services need to work in partnership with other parts of the service landscape to provide a coherent response to the needs of people with autism. However, social care itself also needs to be more joined up. As we have seen, people with autism can fall between the gaps in social care provision, and sometimes receive little or no social care support until their needs escalate to crisis point. More collaborative efforts, at strategic and operational levels,[57] can prevent this happening.[58]

Locally, the key strategic mechanism for this is the Joint Strategic Needs Assessment. These assessments are the responsibility of the local health and wellbeing boards, which bring together local authorities, general practice commissioners, other public and voluntary sector bodies and – via Healthwatch – user and carer representatives.

‘Fulfilling and rewarding lives’ places the joint strategic needs assessment at the heart of joined-up planning for people with autism.[18] The first task is gathering accurate data on the number of people with autism in the local area. From there, local areas, led by the lead commissioners for autism, can jointly plan a commissioning strategy to develop the services that are needed. To do this well, joint strategic needs assessments should include:

- key characteristics such as the age, race and sexuality of people with autism, as well as where and with whom they live
- links with health, education, housing, employment and community groups
- input from children’s services as they relate to people with autism
- facilities for joint training and pooled budgets to allow for as much flexibility as possible.

Lead local commissioners for autism are vital to good planning and joint working. They need to:

- be on mainstream health and social care commissioning bodies as well as autism-specific ones, so that people with autism are not seen as a minority interest
- ensure that all relevant contracts include the requirement to meet the needs of people with autism
- link up with autism charities, social enterprises and user-led organisations

- promote the involvement of people with autism and their carers in service design and delivery
- promote localised, non-residential provision,[35] and good partnership working with housing services
- ensure that local provision is available for people with autism with behaviour that challenges services, including in an emergency
- develop protocols as to where people with autism will receive support, to avoid the gap between mental health and learning disability services
- promote effective information-sharing between and within public bodies and voluntary organisations
- consider the extra costs of autism in their commissioning strategies, and when setting up resource allocation systems.

‘Fulfilling and rewarding lives’ suggests that autism planning should take place in local autism partnership boards, which bring together people with autism, their carers and advocates, service providers and statutory commissioners to look at how services can be improved,[18] and ‘Think autism’ reports that these have been a ‘highly effective means for stakeholders to shape and monitor local delivery of the strategy and statutory guidance’.[20]

Local areas are beginning to make progress with this agenda, and have already begun to self-assess against the goals of ‘Fulfilling and rewarding lives’, looking not just at social care, but also links with employment, housing and other mainstream services, and at locally determined priorities.[59]

Joint strategic needs assessments, resource allocation systems and joint improvement partnerships do not operate in Northern Ireland. For commissioning information, refer to guidance produced by the Health and Social Care Board in Northern Ireland, priorities for action and related public service agreements.[60] Mechanisms for joint working are a focus of the strategic action plan for autism 2013–2020.[28]

Seven quality outcomes from ‘Fulfilling and rewarding lives’

‘Fulfilling and rewarding lives’ [18] sets out seven quality outcome measures against which local areas in England can test how well they are meeting the aims of the Autism Strategy.

These outcomes state that autistic adults will:

- achieve better health outcomes
- be included and economically active
- live in accommodation that meets their needs
- benefit from the personalisation agenda in health and social care, and be able to access personal budgets
- no longer be inappropriately managed in the criminal justice system

- be satisfied with local services
- be involved in service planning.

To help local areas work towards these outcomes, the document also sets out three key ambitions:

- Local authorities and partners know how many adults with autism live in the area.
- A clear and trusted diagnostic pathway is available locally.
- Health and social care staff make reasonable adjustments to services to meet the needs of adults with autism.

Further reading

- [‘Think autism: fulfilling and rewarding lives, the strategy for adults with autism in England: an update’](#) (2014), Department of Health.
- [‘Statutory guidance for local authorities and NHS organisations to support implementation of the adult Autism Strategy’](#) (2015), Department of Health.
- [‘Six steps of autism care \(for children and young people in Northern Ireland\)’](#) (2011), Northern Ireland: Regional Autistic Spectrum Disorder Network for Northern Ireland.

Transition and autism

Transition to adult services and autism

The transition from children's to adults' social care can be particularly difficult for people with autism. In 2010 it was reported that 70 per cent of children with autism identified in the special educational needs (SEN) system were entitled to transition planning due to statements of special educational need.[21] Since then there has been a year-on-year increase in the number of children and young people with autism receiving help at school, and autism is the most common reason for a child to receive a statement of special educational needs.[61] The Children and Families Act 2014 introduced education, health and care (EHC) plans for children and young people from 0–25 years, replacing statements of special educational need. Such plans are intended to be more person-centred and to prepare young people for adulthood, with the focus on transition remaining from year 9 (age 14).[19]

A recent study found that support for young people leaving school remained variable,[62] with some places providing transition support to all students identified as autistic, while others provided support only to young people with greater support needs. Post-education support was less accessible, particularly for autistic young people who were not entitled to adult social care. Guidance for 'Think autism' suggests that even where young people with autism are not entitled to adult social care services, under the Care Act 2014 they should be signposted to other sources of guidance and support in the community.[20]

Young autistic people face the same problems as other groups during transition,[13] namely:

- difficulties maintaining consistent staffing over the transition period
- lack of communication between professionals in different services
- different services switching to adult services at different ages
- fewer, less well-resourced services in adulthood
- paying for services that were free as a child
- carers feeling excluded from consultations about their now-adult family member.

Autism-specific barriers

Some aspects of autism can make transition particularly difficult:

- School provides a structure that many people with autism like, and feel the lack of when they leave.
- Coping with change can be problematic.
- Conceiving of a range of new options can be hard.
- There is a chance of falling through the gaps in adult services for people with high-functioning autism and Asperger syndrome. [63]

- Adult life and expectations, including the world of personal relationships, can carry new challenges. [10, 64]
- There is limited provision of further education options, especially for those who display challenging behaviour. [13,62]

Furthermore, if transition goes badly, people with autism can be stuck in poor-quality services, and have lives that are not as independent as they ought to be.[23]

Improving transition

During transition, services should aim for:[62]

- full involvement of young people with autism and their families in multi-agency transition planning
- respect given to the preferences of young people with autism. Research has found that adaptations to the person-centred approach to consultation were particularly helpful in transition [65]
- better information given to families as young people approach transition
- better communication between adults' and children's services. Under the Care Act 2014, local authorities have a duty to assess young people who are likely to need adult services regardless of whether they have been receiving services prior to transition [19]
- an opportunity for people placed out of area to return home, should they wish
- autism training for transition staff, including staff working in child and adolescent mental health services
- attention paid to the needs of young people with autism who display challenging behaviour [62]
- autism training for workers in employment and training services such as Connexions and the National Careers Service
- differentiation in assessments between support needs and education needs, so that people are not put on academically limited courses due to their communication difficulties
- awareness that, for those who go on to college or university, support needs may need consideration alongside educational needs [66]
- an underlying assumption that young people with autism can lead full lives of their own choosing.

Approaches to transition

In England, transition planning is addressed within a young person's education, health and care plan [67] covering social care, education, health and support into employment, which runs until a person is 25 (for those in education or training – excepting university study). There is also a strong emphasis on professionals having much higher

aspirations for children with disabilities, building on the messages of the previous government's 'Aiming high for disabled children'.^[68]

In Northern Ireland, transition planning is guided by the Education (Northern Ireland) Order 1996 as amended by the Special Educational Needs and Disability (Northern Ireland) Order 2005. Further guidance is contained in the 'Code of practice' ^[69] and a supplement to this issued in 2005.^[70] A priority for action within the autism strategy 2013–2020 and action plan 2013–2016 is the development of multi-disciplinary, multi-agency approaches to transition.^[28]

A government interdepartmental group was set up to take forward strategic developments in the transition process for young people with special educational needs, which includes the needs of young people with autism. The group's report highlights deficits in transition planning and provides a wide range of actions to make improvements in moving across the spectrum of service provision.^[71]

Further reading

- ['Report of the transitions inter-departmental working group'](#) (2006), Department of Education, Department for Employment and Learning and Department of Health, Social Services and Public Safety
- ['Educational provision and support for persons with autistic spectrum disorders: the report of the Task Force on Autism'](#)
- ['Six steps of autism care \(for children and young people in northern Ireland\)'](#) (2011), Regional Autistic Spectrum Disorder Network for Northern Ireland.
- ['Challenging behaviour: a guide for family carers on getting the right support for teenagers'](#) (2011), Social Care Institute for Excellence.

Growing older with autism

Autism was not included in the main European or American classification of diseases manuals until the late 1970s and early 1980s, with Asperger syndrome included even later.^[39] Children were initially the subject of most diagnoses of autism. As a result, few people, who are now older, have a diagnosis of any autistic spectrum condition and gaining a diagnosis for older people can be hard, because it is difficult to draw up an accurate picture of early years' development. Many older people with autism will therefore have inaccurate diagnoses, or will be viewed as simply odd or eccentric. For some, their difficulties adapting to change are dismissed as a product of being older, and therefore 'stuck in their ways', or are attributed to mental health problems or dementia, which can lead to inappropriate treatment.^[39]

There is also little research into the needs of older people with autism.^[72] Recent studies ^[73,74,75] indicate that they are socially isolated, and have difficulties sustaining employment and relationships.

Diagnosing older people with autism is important, so that they can benefit as others do from the greater understanding and access to services that a diagnosis can bring.^[72] People face some key transitions as they age, such as retirement and bereavements, and it is important they receive appropriate support.^[20]

Loss of carers

A significant transition faced by many people with autism as they get older comes when their parent carers are no longer able to support them at home. Many autistic people continue to live at home with carers well into adulthood, and parent carers are therefore likely to be nearing and entering old age while still providing care to people with often very high needs.[35] The potential for sudden breakdowns in caring arrangements is high, and too many people with autism may find themselves hurriedly placed in settings that may be expensive, distant, inappropriate, or all three. Other people may be left living at home without adequate support. This is a key cause for stress and concern for parents and carers as they approach older age.[75]

It is important, therefore, that careful planning, involving the person with autism and their family, takes place well in advance of a change to the family situation.[76] This will help to address the concerns of both the autistic person and their carers. Emergency plans, detailing what support will be put in place for someone if their care arrangements break down, can alleviate anxiety, and lessen the likelihood of an emergency residential placement.

Accessing healthcare

Older people experience the same difficulties with accessing healthcare that we outlined in the section on 'Joint working', and this can lead to avoiding healthcare until absolutely essential.[72] Entering the healthcare system at the point of severe health decline can result in expensive nursing home placements or hospitalisations. People may also be less likely to ask for adaptations to their property, or for home help, 'Think autism' sets one of its priorities around improving services for older people,[19] and the Care Act 2014 includes a duty to provide independent advocacy services for those who find navigating the care system difficult and have no support networks to assist them. Older people with autism may find this helps them to access services at the point of need.

Early intervention and prevention in autism

Eligibility and autism

Some of the difficulties faced by people with autism could be addressed or reduced if low-level, often relatively inexpensive services were provided promptly.[35,45] This notion of early intervention is often hampered by what people with autism sometimes experience as inflexible and reactive services, and a lack of knowledge about the ways autism might affect a person can limit the support they are offered.[13]

Care eligibility can be difficult to negotiate for autistic people, and previous systems such as Fair Access to Care Services (FACS) or, in Northern Ireland, 'Care management, provision of care and charging guidance' [77,78] measured care eligibility against risk to independence. Most local authorities only provided services to people whose needs were high, which made the provision of early intervention services less likely.

The Care Act 2014 has as one of its focuses the need for preventative services ('preventative' does not mean services that aim to prevent autism but those that aim to prevent social care needs from escalating), emphasising in its guidance 'the importance of preventing or delaying the development of needs for care and support and the importance of reducing needs that already exist'.[15] This means that even where there is no eligibility for continuing care and support, there is still a duty to promote wellbeing through signposting to alternative services in the community such as voluntary organisations.

- [Definition of eligibility for the Care Act 2014](#)

Primary, secondary and tertiary autism services

The Care Act guidance breaks preventative services into primary, secondary and tertiary categories and these move from the promotion of more general services which may be purchased by the carer or autistic person, to more focused interventions aimed specifically at particular groups.

Primary prevention promotes wellbeing in the community as a universal service. This includes:

- good quality information
- support for safe communities
- reducing isolation or loneliness
- promoting a healthy lifestyle
- thinking ahead about future support needs.

Secondary prevention promotes more targeted early intervention. This may include:

- help with managing money
- handyman or gardening services
- home adaptations to make independent living more manageable.

Finally, tertiary prevention promotes targeted interventions aimed at improving the lives of people with disability or established health conditions. These may be:

- specific training programmes or reablement services
- respite care for carers
- emotional support or stress management classes.

The focus in recent guidance on diagnosis has an early intervention aspect, as the sooner people are accurately identified as having autism, the sooner appropriate, well-informed support can be provided.[36] The insistence in 'Think autism' that a person receiving a diagnosis of any form of autism must be offered an assessment of need means that people with high-functioning autism or Asperger syndrome have at least overcome one hurdle to getting the support they need, even if they still have to have eligible wellbeing needs under the Care Act 2014. The expectation here that local areas will provide a universal information and advice service [79] should also mean that people with autism can be pointed in the right direction for accessing help.

Intervening early and autism

Providing prompt, preventative services can work for people at different points on the autistic spectrum. It can benefit people with high-functioning autism or Asperger syndrome, who may find that support with social skills can prevent social isolation and attendant mental health difficulties. It can also help people with autism and complex learning disabilities or challenging behaviour, for whom intensive support within the home, coupled with good respite care, can prevent placement in expensive residential care.

A good-quality response at the point of diagnosis – prompt advice, practical support and help finding the right ongoing support – is a key part of early intervention, and likely to be of benefit to all people with autism and their families.[35] For many, these small amounts of practical support will then be sufficient to help them manage in society.[13] Many people with autism choose to spend personal budgets on just this sort of support.[19] Help with tasks such as bill-paying and filling out forms can make the difference for some people between living independently, and stressful visits from bailiffs and to courtrooms.

Developing capacity for low-level early intervention services could lessen the lengthy battles for support that many people with autism and their families have had to wage. This helps them, but could also benefit local services in terms of costs and pressures on staff.[13] National Audit Office research[35] indicates that supporting more people with high-functioning autism and Asperger syndrome quickly becomes cost neutral, and can potentially lead to long-term savings from higher tax incomes and reduced benefit payments as people are supported into employment. It also reduces mental health and criminal justice costs as people are supported before they reach crisis points in their lives.

Specialist care teams

The National Audit Office report [35] highlights the potential benefits, for outcomes and budgets, of specialist care management teams for people with high-functioning autism

and Asperger syndrome. Where these were available, evidence suggested that people who have access to these teams:

- find getting a diagnosis easier
- lead more independent lives
- are more likely to work
- are less likely to have mental health difficulties
- are more likely to have carers who are in work.

Furthermore, the research showed fewer people with high-functioning autism living in residential or inpatient provision in those areas that have a specialist team than those without – 1 per cent against 7 per cent. This is worth noting, because:

- people with autism are often placed in expensive residential care
- it costs much less to support a person in their own home than in residential care
- placements are often far removed from a person's family and community
- out-of-area placements are relatively more expensive than local ones,[80] including in costs to families and friends as well as to the social networks of the person
- out-of-area placements commonly reflect a lack of local provision or expertise, and are often associated with poorer access to specialist healthcare [23, 35]
- money spent on out-of-area placements is money that cannot be spent developing local expertise,[10] which may benefit all people with autism in a local commissioning area.

Commissioning high-quality home-based and respite support can therefore help people live in the community and lead to better outcomes at lower costs. Specialist advocacy, befriending services and support within the criminal justice system all have the potential to improve outcomes for people with autism.[20,81]

Support for skills and activities for people with autism

Social interaction is difficult for people with autism.[82] The National Autistic Society reports that the main services requested by autistic adults in its 'I exist' study [37] were social skills training, social groups and befriending.[48] For many people with autism, therefore, training in social skills, and the opportunity to engage in social situations in which they feel comfortable, can be important in preventing them from feeling isolated and unable to cope. Such training often works better in a specific context such as part of the transition from school [62] or in the workplace; in isolation it can be less effective.

Our research showed people were fairly consistent in wanting support in order to engage with social activities, but more varied in exactly how they socialised currently, and what else they wanted by way of social activities.[13]

People with autism most commonly socialised with family members and friends, but we found that the next most common arena for socialising was online.[13] As a medium in which people can exert more control over the timing, pace and flow of both giving and receiving information, as well as a space to find people with similar interests, interacting online may have real benefits for many people with autism.[62] A common misconception is that autistic people do not seek friendships. Studies have shown that this is not the case and that many people would welcome support in this area.[13,82]

Difficulties with public transport and low incomes can make socialising problematic.[33,82] Other barriers included a lack of suitable activities, not feeling accepted and being worried about other people's perceptions.[13] For some, this can lead to a preference for autism-specific social spaces, perhaps structured around certain themes or interests.[45,62] Others, however, express disquiet about groups targeted at people with autism, and stress the value of ordinary activities, asserting their right to be accepted within them.[13] Still others found buddy schemes very helpful. Here, an identified person or 'buddy' supports them as they negotiate new situations. Some people with autism have benefited from mentoring and life coaching.

In all support for social activity scenarios, however, it is worth noting the following.

- People may need to build up to social support. There often needs to be an extended period of time receiving support in the home before the person is confident to go out with support staff.
- People need to have a choice in who supports them so that they feel comfortable socialising with them, and need to be able to state their preferences over common interests.
- Schemes need to have confident, consistent staff with training in a range of issues, such as additional mental health problems.
- Poor social support can lead to increased feelings of rejection or replicate previous failed relationships.
- Carers' concerns need to be listened to, as they may be able to anticipate difficulties and may be anxious to start with.

Personalising autism services

Benefits of personalising autism services

Personalisation can have a positive impact on the lives of people who use it. Coming up with person-centred plans and goals can bring people together, energise them and create a positive environment for people to think about what they want and how to get it.[58]

For many adults, a diagnosis of autism is arguably only as useful as the personalised, appropriate services to which it then leads, and indications are that specialised, individualised services can achieve better outcomes.[10] Some people with autism require flexible services completely tailored to them as individuals for their needs to be met effectively. Social care services may need adjustments in order to be suitable for autistic people. For example, large, shared residential homes can be inappropriate for people who have complex social, communication and sensory needs.[45]

Giving people with autism and their support network choices over who supports them and how this should happen, through a personal budget, creates an opportunity to get exactly the right person for the job, including, where appropriate, a family member or a friend who knows the person really well.

Barriers to personalising autism services

Autistic people who used a personal budget were generally positive about the personalisation of their social care, with over 80 per cent viewing the budget as working well, or well 'to some extent'. [13] However, until recently, very few autistic people had access to a personal budget, and further research will be needed to see how successfully they are implemented under the Care Act 2014.

Various barriers to personalisation were cited by people in our research:[13]

- the bureaucracy involved in applying for something about which they knew relatively little: 'I expected the application process to be stressful and probably with no net financial benefit'
- concern that personalisation would be used by funding authorities to cut care packages
- anxiety that the underpinning philosophy of choice and control was being undermined by the insistence that all users of social care should live independently
- an underdeveloped market for personalised support for people with autism
- fear that personalisation would increase the carer burden, with extra bookkeeping and employment problems.
- fear of financial exploitation.

These concerns reflect wider anxieties about how people with autism will be affected by personalisation. Certainly there are barriers:

- Eligibility criteria and charging guidance may act as a barrier to any social care, not just personalised services.
- At a time of cuts, the costs of providing really good support to people with autism might not be reflected in any care packages, including personalised ones.
- Self-assessment forms and resource allocation systems need to be subtle enough to capture the nuances of autism, given the difficulty people may have in conveying their needs accurately, unless supported to do so.
- Personalisation may lead to the closure of some existing services, which autistic people may find disconcerting, and the micro-commissioned services that replace them are not yet established as being able to meet autistic people's needs.[46]
- Personalisation may lead to greater social isolation and vulnerability as established groups are closed down.[10]
- People with autism may find some issues inherent in employing personal assistants difficult, in particular maintaining appropriate boundaries.
- There may be more gaps in service delivery due to sickness/staff training, when people have just one or two people who support them. Good planning needs to be in place to prevent this.
- Professionals sometimes lack sufficient knowledge of personalised options, or of autism, to make personalisation work.[33]
- The world of person-centred planning uses vague and metaphorical terms such as 'health passports', 'dreams', 'doughnuts' and 'circles', which often make no sense to an autistic person.[13] Adjustments therefore need to be made.[5,65]
- Some professionals see personalisation as a passing fad, a threat or a criticism of existing ways of working, and of them by extension.
- Employing a personal assistant to work alone with a person with autism could be overly intensive for both parties.
- Budgeting can be hard for people with autism, and this combined with difficulties understanding the motivations of others may make them vulnerable to exploitation.

Research [83] found that person-centred working can also be hampered by inflexibility within systems, poor communication between agencies and with those who use services and their families, and ever-tighter financial restrictions. Families have expressed the view that there is a danger that personalisation can fail to focus on the person within their social circle, and leaves parents and siblings feeling cut off from those receiving support.[84]

Solutions for personalising autism services

Managers and commissioners need to take advantage of the opportunities available in the changing social care system to enable people with autism to make use of personalised services. Policy in England calls for a universal offer of advice and support in finding appropriate assistance, so personalisation ought to have something to offer even to those people with autism who do not have eligible needs after assessment. The government's continued call for more timely diagnosis,[19] alongside the Care Act's duty to provide a social care assessment against wellbeing criteria for everyone receiving a diagnosis [15] are likely to bring more people with autism into the social care system, and give them the chance of a personalised package. For those in need of a substantial care package, including medical support, a personal health budget may be allocated alongside, or instead of, a personal budget.[86]

Resource allocation systems need to allow for high-quality, flexible support, and should cover the costs of brokerage [87] and allow for staff and organisations with expertise in autism to be purchased if necessary.[88] Local leadership through the autism partnership boards in England should be in place to make sure this happens,[20] and should also check that resource allocation system-based provision is not so slow to set up as to cause undue anxiety to people with autism.

For some of the bureaucratic hurdles involved in personalising support to be overcome, advocacy and independent brokerage need be available to people with autism,[46] alongside good-quality information about choices and options. And, of course, information about the options is not enough: people with autism need the options to be of good quality and varied, and to include well-trained personal assistants who understand autism, and who can understand them.[45]

A local structure

Developing a local structure for personalised services can best be done in partnership with people with autism and their families. User-led organisations can also help develop acceptable services for people with autism to purchase.

Autistic people are likely to benefit from some more managed forms of personal budgets, such as:

- personal trusts, in which money is held by people close to the user
- direct payments
- individual service funds, in which a service holds a budget on behalf of, and for the sole use of, the autistic person.[15]

Local advocacy services with an understanding of people with autism need to be available to ensure that they receive good-quality advice about the options, and social care staff need to be familiar with the Mental Capacity Act 2005 (or relevant mental capacity legislation) as a way of ensuring that people with autism are properly and legally supported to make decisions.

Personalisation has the potential for helping autistic people to maintain meaningful, healthy lives. However, service providers need to ensure that a person-centred approach takes into account the communication needs of the autistic person, and that a

strengths-based approach is taken in order to promote their wellbeing and build on their personal capabilities and relationships.[41]

Further reading

- ['A manual for good social work practice: supporting adults who have autism'](#) (2015), Department of Health.
- ['Mental Capacity Act resource'](#) (2009), Social Care Institute for Excellence
- ['Strengths-based approaches for assessment and eligibility under the Care Act 2014'](#) (2015), Social Care Institute for Excellence.

Work as a route to choice and control for people with autism

Only 15 per cent of people with autism are in full-time employment,[54] so too many are financially and socially excluded by not working.[20] Employment can be a powerful mechanism in promoting control over an individual's life. People with autism, with appropriate support, can really benefit from working.[82] The National Autistic Society's specialist employment service has had good success in finding work for people with autism, placing 70 per cent of those they work with into employment.[82] Autistic people are often diligent, good at paying attention to detail and unlikely to move from job to job.[57]

- Mentoring schemes at work can be helpful in settling people into new roles.
- Social support needs to be flexible to fit around working hours.
- Services should not presume that someone who works full time does not have other needs.
- People may need extra support during the transition between state benefits and paid employment.
- People may need extra support during transitions between jobs or if their job role changes.

Evidence that work leads to genuine social inclusion for those with autism is slight,[10] suggesting that more needs to be done to change employer and employee perceptions about autism. Autistic people report that employment support staff also need more knowledge about the skills and abilities they may have in order to avoid being placed in inappropriate roles; for example, placing someone with high-functioning autism in a job set up for someone with a learning disability.[62] 'Think autism' proposes further autism awareness training for Department for Work and Pensions staff such as disability employment advisers, and has developed a 'Hidden impairment toolkit' in partnership with employers and user organisations in order to make employment advisers, administrative staff and prospective employers more aware of the sorts of differences that autistic people present with. Engagement by employers with local autism partnership boards should also be encouraged.

Further reading

- ['Valuing people now – employment: supported employment and job coaching, best practice guidelines'](#) (2011), HM Government.

Carers of people with autism

The pressures for carers of people with autism

The pressures of living with and supporting people who see the world very differently, who can appear unresponsive or who can be destructive and violent, can be considerable. Such pressures are typically lifelong, and can persist whether or not the autistic person lives with their carer. Some autistic adults will not see that they need support, even if their families are under strain.[10] Sometimes support services designed for a carer have been blocked by the person with autism, for example by not letting people into the house. Carers' benefits can feel like scant recompense,[13] especially in those families where there is more than one person with autism.

These pressures have often been coupled with the pressure of battling with organisations for support.[13] This battle applies both to services for the autistic person and perhaps even more so to services for carers themselves.[33] The job of caring for someone with autism can act as a powerful barrier to life and employment options, and is a situation that leads some carers to the edge of mental and physical wellbeing, and some into ill-health.[13, 89] It is important to remember that autism seems to have a genetic component, so carers may be looking after more than one person with autism or may be autistic themselves.

Of the 124 carers who responded to our survey, only three per cent found gaining access to carers' services easy. Many had not even tried, feeling the struggle was not worth the likely benefit. Carers reserved their energies for seeking services for the person with autism they support, as this was challenge enough. Carers found access to social activities, diagnosis, education, housing, employment and social services hard to come by for the autistic person.[13]

Accessing these services often requires doggedness. When services were accessed, carers often felt that the people employed in them did not know enough about autism.[35] Many carers acknowledge that they feel concern as their offspring take new steps towards an independent lifestyle, but resent what they perceive to be the view of some professionals that they are trying to hold back their family members as they move to independence.[13, 42] Several studies have shown how parents of autistic people support independent living for their children, and that their support is welcomed by those children.[62, 75, 89] The development of personalised services makes some carers fear they will be marginalised further or burdened with extra tasks and responsibilities.

Support for carers of people with autism

A carers' assessment is the vital first step in a carer accessing the support they need, yet too few carers of people with autism have received one.[13] Under the Care Act 2014, carers are given equal status in relation to eligibility for assessment of support needs. A diagnosis of any form of autism should act as a trigger to offer a carers' assessment to all those supporting the diagnosed individual.

Carers' assessments can be offered even if the person with autism has refused an assessment for themselves. If a carer refuses an assessment when offered, they are able to ask for this at a later date.[15] This also applies if a diagnosis of autism has

been received at an earlier date, and assessment found no eligibility for social care support. In Northern Ireland, carers who provide a substantial amount of care on a regular basis for someone with autism have the right to a needs assessment when requested. These rights and duties are set out in the Carers and Direct Payments Act (NI) 2002.

The concern that some parents and carers feel about their family members' move towards independence can be lessened by the presence of supportive and skilled professionals, who must:

- listen, and take on board the experiences that family members have [13]
- recognise the incredibly in-depth, detailed knowledge that carers have and that this is not limited to parents – siblings and partners figure here as well [13,75,84]
- understand the love and sheer investment of emotion and time over many, many years that most carers bring to any discussion about the person with autism [48]
- empathise with the likelihood that carers may be drained from battles fought over the years, and may display a cynicism about the ability or willingness of professionals to help
- respect the different views an autistic person and their carer may have about the person's needs, and make clear in assessments who is expressing what opinion
- recognise that carers may be particularly anxious about the future, when they are no longer able to oversee what is going on for their family member [89]
- plan early with families for what may happen, to help allay these concerns – this includes involving siblings fully in this planning. [84]

Some carers may need help in identifying all the support that they give, as it can be subtle and fluctuating. Carers sometimes live according to the person with autism's needs, and prioritise these over their own. They may do a lot of things unconsciously in relation to mediating between the autistic person and the outside world, such as answering all telephone calls or arranging appointments.

The need for clear communication with autistic people is mirrored by the need to communicate clearly with carers, and to avoid professional jargon which can act as a barrier to collaborative working.[48] This matters, because liaising with those closest to the autistic person can give professionals a much fuller picture of their support needs.

Carers and family members often become expert in the particular needs of the person they support. They can be hugely well informed about autism more generally, and many carers also become experts in how social care systems operate.[13] This makes them ideal partners to work with services. Carers of people who have been recently diagnosed, however, may benefit from information and advice on autism.

Collective efforts by groups of parents can be a useful mechanism for achieving change. This may be by:

- advising local authorities/trusts over the provision of services
- setting up mutually supportive group meetings
- using the power of collective complaints to address poor access to services for autistic people and carers.[13]

Some carers in our study had set up advice services themselves when they found these lacking in their local community. The renewed call in 'Think autism' for local autism partnership boards to include a full range of stakeholders provides a key opportunity for carers to have a voice in their community.[19]

The 15 priority challenges identified in 'Think autism' through consultation with autistic people includes one specifically aimed at the families who do so much to support their loved ones with autism: 'I want to know that my family can get help and support when they need it'.[19]

Local authorities need to prioritise carers' wellbeing, as their knowledge, support and hard work go a long way towards improving the lives of adults on the autistic spectrum. The Care Act 2014 aims to go some way to doing this, but it is too soon after its introduction to evaluate how successfully.[20] The Carers Strategy for England, 'Recognised, valued and supported',[90] emphasises the expertise that carers have, but stresses that they should be entitled to dignity, financial wellbeing and a life beyond caring. Other key aspects of this strategy include:

- better information on employment and benefits issues, and on the condition in question
- better services for the cared-for person
- less laborious assessment processes
- more, and more personalised, respite breaks
- more involvement of carers in service planning and delivery, and their input into joint strategic needs assessments (not available in Northern Ireland)
- services that do not call for help whenever there is a problem, but properly support a person, and allow carers time away from caring
- more flexible working for carers
- more training for carers.

Were all or most of these available to carers of people with autism, it would be reasonable to expect that the challenges of caring, and the attendant physical and mental health difficulties, may be lessened.

Further reading

- ['Care and support statutory guidance issued under the Care Act 2014'](#) (2016), Department of Health.
- [Strengths-based approaches](#)

Further reading

Autism publications from the Department of Health

- [‘Better services for adults with an autistic spectrum disorder’](#) (2006)
- [‘Services for adults with autistic spectrum conditions \(ASC\)’](#) (2009)
- [‘A better future: a consultation on a future strategy for adults with autistic spectrum conditions’](#) (2009)
- [‘Fulfilling and rewarding lives’](#) (2010)
- [‘Towards "Fulfilling and rewarding lives"'](#) (2010)
- [‘Implementing "Fulfilling and rewarding lives": consultation on guidance’](#) (2010)
- [‘Implementing "Fulfilling and rewarding lives": statutory guidance’](#)(2010)
- [‘Fulfilling and rewarding lives – the strategy for adults with autism: evaluating progress’](#) (2011)
- [‘Transforming care: a national response to Winterbourne View hospital’](#) (2012)
- [‘Think autism: fulfilling and rewarding lives, the strategy for adults with autism in England: an update’](#) (2014)
- [‘Statutory guidance for local authorities and NHS organisations to support implementation of the Adult Autism Strategy’](#) (2015)
- [‘No voice unheard, no right ignored: a consultation for people with learning disabilities, autism and mental health conditions’](#) (2015)

Other key government policies/publications

- HM Government (2005) [‘Mental Capacity Act 2005’](#), London: The Stationery Office.
- Department of Health (2009) [‘The Mental Capacity Act deprivation of liberty safeguards’](#), London: Department of Health.
- Department of Health (2009) [‘Valuing people now: a new three-year strategy for people with learning disabilities’](#), London: Department of Health.
- [‘UK Initial Report on the UN Convention on the Rights of Disabled People’](#) (2009), London: Office for Disability Issues.
- Office for Disability Studies (2009) [‘Independent living: a cross-government strategy about independent living for disabled people’](#), London: Office for Disability Studies.
- Department for Work and Pensions (2010) [‘Work choice: supporting disabled people in employment’](#), London: Department for Work and Pensions.

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- Office for Disability Issues (2011) 'Right to control', London: Office for Disability Issues.
- Care and support statutory guidance issued under the Care Act 2014(2014), London: Department of Health.

For more information on welfare reforms that may have an effect on people with autism, such as the introduction of employment support allowance and changes to housing benefit, see www.dwp.gov.uk.

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Autism: Improving access to social care for adults

This guide helps people in the health and social care sector who work with adults with autism to increase their awareness, knowledge and understanding. Autism is a lifelong developmental disorder, referred to as a 'spectrum condition' since some people with autism have profound difficulties and require specialist support, while others live largely independent lives

Please note that throughout this guide, we refer to the condition as autism, rather than as autistic spectrum condition (ASC) or autistic spectrum disorder (ASD).

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