



Improving access to social care for adults with autism



The Social Care Institute for Excellence (SCIE) was established by Government in 2001 to improve social care services for adults and children in the United Kingdom. We achieve this by identifying good practice and helping to embed it in everyday social care provision.

SCIE works to:

- disseminate knowledge-based good practice guidance
- involve people who use services, carers, practitioners, providers and policy makers in advancing and promoting good practice in social care
- enhance the skills and professionalism of social care workers through our tailored, targeted and user-friendly resources.

First published in Great Britain in October 2011
by the Social Care Institute for Excellence

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About this guide

This guide is primarily for frontline, managerial and commissioning staff in the social care sector. Most sections are relevant for all of these groups, while some are targeted at either people working on the front line or more senior staff.

This is made clear in the section titles. The guide is built upon *Access to social care for adults with autistic spectrum conditions*, a practice enquiry conducted with people with autism and their families by the University of Sussex, on behalf of SCIE. It is informed too by SCIE Research Briefing 32: *Access to social care and support for adults with autistic spectrum conditions (ASC)*, as well as drawing upon other work and opinion identified by SCIE staff as relevant. It makes extensive reference to Fulfilling and Rewarding Lives, the government's autism strategy, and its supporting documents.

The guide was drawn up with the help of an Advisory Group, which included people on the autistic spectrum, their carers, representatives of ADASS, Autism London, and the National Autistic Society, and academics.

For readers from Northern Ireland

Please note that the policy context of Fulfilling and Rewarding Lives in this practice guide is specific to England. The guide, however, contains guidance on good practice in social care and social work with autism that is relevant for readers from Northern Ireland.

Policy variations/exceptions in the guide

Please note that the following policies/guidance do not apply to Northern Ireland. The arrangements or equivalents for Northern Ireland, where applicable, are listed.

Fair Access to Care Services - please refer to the DHSSPS'Circular HSS (ECCU) 2/2008: Regional access criteria for domiciliary care'. Wider guidance covering assessment and reviews is contained in the DHSSPS'Circular HSC (ECCU) 1/2010: Care management, provision of care and charging guidance'.

Joint Strategic Needs Assessments - the nearest equivalent in Northern Ireland would be the local strategic plan of each of the five Health & Social Care Trusts.

Mental Capacity Act - currently there is no mental capacity legislation in Northern Ireland; however, the forthcoming mental health legislation, due to be implemented during 2011–2012, will cover mental capacity.

Mental Health and Learning Disability Standard Contracts do not apply to Northern Ireland.

Putting People First - in Northern Ireland, refer to: '**People first community care in Northern Ireland in the 1990s**'

Resource Allocation Systems - in Northern Ireland, personal budgets are not used, however direct payments (which are a form of personal budgets) are provided to service users. Similar to Resource Allocation Systems, the criteria for direct payments used in Northern Ireland are: Carers and Direct Payments Act (Northern Ireland) 2002; 'Direct payments legislation and guidance for Boards and Trusts' (DHSSPS, 2004); and the DHSSPS 'Circular HSC (ECCU) 3/2009: Guidance on accounting and monitoring requirements for payments made under the Carers and Direct Payments Act (Northern Ireland) 2002'.

Support and aspiration: A new approach to special educational needs and disability - for Northern Ireland, please refer to guidance on special educational needs provided by the Department of Education, further information from Department of Employment and Learning and/or Department of Education, Department for Employment and Learning and Department of Health, Social Services and Public Safety (2006) 'Report of the Transitions Inter-Departmental Working Group', Belfast: Department of Education, Department for Employment and Learning and Department of Health, Social Services and Public Safety.

Think local, act personal has no current equivalent in Northern Ireland.

Department for Work and Pensions - the functions of this department are covered in Northern Ireland by the Department for Social Development (www.dsdni.gov.uk).

Acknowledgements

The Social Care Institute for Excellence (SCIE) would like to thank the following people and organisations for their support and contribution to the development of this guide:

- Department of Health, who commissioned the work
- National Autistic Society
- Melissa McAuliffe - East London NHS Foundation Trust
- David Shamash - person with Asperger's Syndrome
- E.E. Jones - relationship coach and public speaker working from a unique perspective of a woman on the autistic spectrum
- Alexia Green - graduate with a BPhil in Autism (University of Birmingham)
- Imogen Taylor - University of Sussex
- Tish Marrable - University of Sussex
- Samantha Bond - University of Sussex
- Donna Addy - University of Sussex
- Marie Bremmers - Autism London/Grandparents Plus
- Richard Mills - National Autistic Society/Research Autism
- Lesley Waugh - National Autistic Society
- Zandrea Stewart - ADASS
- Jacqui Jackson - carer

Key recommendations for practice

'If you've met one person with autism, you've met one person with autism.'

(often attributed to Stephen Shore - academic and expert by experience on autism and Asperger's Syndrome)

- Greater understanding of autism among the social care workforce is really important, but it needs to go hand-in-hand with in-depth knowledge of the individual with autism.
- Better awareness of autism in the social care sector can help people get a diagnosis of autism, and get timely and appropriate support when they are diagnosed.
- Staff supporting people with autism need to make adjustments in how they work, plan and communicate, with people with autism and with each other, so that services can be more accessible to people with autism.
- Managers and commissioners of services also need to be flexible, creative and collaborative in how they meet the needs of people of autism. People with autism whose behaviour challenges services, and those with Asperger's Syndrome or high-functioning autism, in particular need better access to services.
- Good support is vital when people with autism experience significant life changes.
- Frontline and senior staff need to work with people with autism to enable them and their families to make the most of personalisation.
- Support with social interaction and practical everyday living tasks can address some of the needs people with autism commonly have, at relatively low cost.
- Multi-disciplinary specialist autism services can provide good outcomes for people with autism. The carers of people with autism typically know them extremely well. Professionals should offer carers support in their own right, and work in partnership with them to provide the best possible assessment and service provision.

Introduction

In this section we explore:

- what autism is, and who has it
- the barriers people with autism face in trying to use services
- Fulfilling and Rewarding Lives – the national strategy for England to improve the lives of people with autism.

What autism is

People with autism have said that the world, to them, is a mass of people, places and events which they struggle to make sense of, and which can cause them considerable anxiety. (2)

Autism* is a lifelong developmental disability. Some people have severe autism, and require a lot of specialist support; others exhibit mild characteristics of autism, and live largely independent lives. This means that autism is often referred to as a spectrum condition. Many people with autism also have a learning disability, but a roughly equal number do not. This latter group is sometimes known as having high-functioning autism, and many have a diagnosis of Asperger's Syndrome, which is a form of autism. Other diagnoses on the autistic spectrum include atypical autism and PDD-NOS (pervasive developmental disorder - not otherwise specified).

All people with autism have difficulties in three areas. This is known as the 'triad of impairments'. People with autism have:

- **difficulties with social interaction**, and find it hard to instinctively understand, or recognise, how other people are feeling. They find it hard also to express their own emotions. This can make getting on with people problematic and highly stressful.
- **difficulties with social communication**, and struggle with verbal and non-verbal language. This varies enormously - some have no speech while others have language but it is impaired, for example they may take what is said literally, and misunderstand body language, humour and double meanings. Some people use limited body language.
- **difficulties with social imagination**, and without a clear structure do not easily conceive of alternatives to their daily routine, imagine what might happen next in their lives or organise themselves. They find it hard to interpret what others may be thinking, or to engage in imaginative activities. People may have limited coping strategies and apply them inappropriately, or may not be able to identify risks consistently.

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. They might therefore prefer their own company, so avoiding unpredictable and stressful situations, even though they may still crave affection. While many people with autism have good

language skills, others will speak little or not at all. People with autism typically prefer communication to be simple and clear.

Many people with autism also have (2):

- sensory sensitivity - over- or under-sensitivity to things such as light, sound and heat, or certain tastes, textures or smells
- problems with motor skills or balance
- a need for structure - perceiving the world as a muddled chaos, people with autism sometimes impose their own routines in order to help make sense of it
- narrow interests - some people with autism can develop a very close interest in a particular topic or pastime, often becoming extremely knowledgeable in it. This can be a strength that opens career prospects, and differs from obsessive behaviours and rituals, which usually result from anxiety. Special interests may also result in some risky behaviours such as spending money excessively or exclusively on those interests, or spending excessive time taking part in an interest and missing meals or sleep
- a focus on detail - this is also a strength, which can enable high levels of achievement in certain fields. 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 ways to mask their difficulties, or have carers who help to mediate difficulties so well that they are not initially apparent to a professional assessing them.

The spectrum nature of the condition and the idiosyncrasy of some people's needs make it unhelpful to over-generalise about autism. They also make 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.

* Throughout this guide, we refer to the condition as autism, rather than as autistic spectrum condition (ASC) or autistic spectrum disorder (ASD).

How many people have autism?

- An estimated 400,000–500,000 adults have autism in the United Kingdom (UK). This represents 1.16 per cent (3) of the entire UK population.
- 20–33 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) (4). This figure excludes the many people with autism who do not use social services, often because they are excluded.
- A King's College London report (5) estimates that the cost of autism in adults is £25.5 billion per year (59 per cent in services, 36 per cent in lost employment and 5 per cent in family expenses).

- The prevalence of autism appears to be increasing, but 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 - who carry out diagnoses.

Barriers to services for people with autism

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 ASC, affecting decisions about help and support. (6)

Fundamental barriers exist for people with autism in engaging with the world around them. Many experience that world as chaotic and complicated, where people communicate in confusing or upsetting ways, and everyday places such as supermarkets, streets and hospitals can be forbiddingly noisy or unpredictable. It is not a world designed by or for people with autism. Until that world makes genuine efforts to accommodate people with autism, by understanding the condition, and making adjustments accordingly, then barriers to accessing it will remain.

Our work with the University of Sussex into the particular obstacles to accessing social care highlighted these fundamental barriers. It also showed that for many people with autism, and their carers, it is a wearying battle to get the social care they need (7). Difficulties can be even greater for people with autism who display behaviour that challenges services, or who have needs that cross the boundaries of several different services. People may get support from one committed professional, whose helpfulness appears to be in spite of the system in which they operate (7), but the system itself is seen as ill-informed, complex and set up in ways that exclude or alienate people with autism.

Problems include:

- a lack of awareness about autism, among 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 (8), which sometimes seems shaped by a sense that a disability must have a physical manifestation. It also relies 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's Syndrome from social care, because they do not have an IQ of 70 or below, the cut-off point for most learning disability services, or a severe and enduring mental illness, which excludes them from mental health services

- many services, such as drug and alcohol services, not feeling confident in offering a service and trying to refer people with autism to specialised services. These specialised services are scarce, and can be geographically or financially difficult to access
- many social services having introduced generic teams, which have separate teams for initial assessment and for ongoing care. This lack of consistency in staffing can be difficult for people with autism.

People with autism who do have a learning disability are generally supported by learning disability services. Here, they are assessed as to whether their needs are sufficiently critical or substantial to require services, under guidance on prioritising social care (9). Often this works well, but assessors sometimes lack sufficient awareness of autism to do the job properly. The paperwork used - assessment forms, or Resource Allocation Systems, which allocate funds for personal budgets* - 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.

Some people's needs can be met creatively and flexibly, and in ways that are not expensive. Some people with autism do have really complex needs, though, and meeting them can involve skilled staff or intensive support. This can be costly, and under-funded care packages are another barrier to a good quality of life for some. This is a concern at a time when councils/trusts are having to reduce what they spend.

Fulfilling and Rewarding Lives is the national strategy for England aiming to address some of these barriers, and it is this that we look at next.

* Personal budgets do not operate within Northern Ireland, however direct payments are provided.

Fulfilling and rewarding lives

'All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents.'

(The vision for adults with autism set out in Fulfilling and Rewarding Lives (10))

Fulfilling and Rewarding Lives (10) is the governmental strategy for improving outcomes for adults with autism in England. It calls for a societal culture shift, so that the equality and human rights of people with autism are respected. To help improve the quality of life for people with autism, it sets out the need for better:

- autism awareness
- training for those working with people with autism
- 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 has a clear narrative: raise awareness among professionals; train those who play key roles in the lives of people with autism; make sure diagnostic services are available; and ensure that good planning and leadership are in place so that good local services can be provided.

The strategy arises from the Autism Act 2009, and builds on a number of recent government publications on, or relevant to, autism. For more details of the policy context, and the provisions of Fulfilling and Rewarding Lives, see the Policy context section.

The strategy is backed by statutory guidance, 'Implementing Fulfilling and rewarding lives'(11). Both the strategy and guidance call on public bodies, including social care organisations, 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 (10), and call for a better use of existing law, and policies such as Valuing People Now (12) and Think Local, Act Personal(13), to support people with autism.

Importantly, the strategy and guidance make clear that a diagnosis of any autistic spectrum condition, including Asperger's Syndrome or high-functioning autism, is a reason to assess somebody for services.

As well as aiming to improve public services for people with autism, the documents call for all mainstream services - such as transport, leisure and employment - to get better at adjusting to, and meeting the needs of, people with autism.

The statutory guidance allows for local discretion in how the strategy is implemented (11), and there is concern that a lack of funds and central direction may hamper some of the key aims (14, 11). Nonetheless, local authorities, and most NHS bodies, will need to abide by the guidance, and improve their:

- levels of autism awareness
- diagnosis and assessment pathways
- transition arrangements for young people with autism

- local planning and service delivery (11).

Progress has begun in local areas towards meeting these goals. If local partners succeed, the experience of people with autism who use these services can reasonably be expected to improve. This guide shows what people with autism find problematic with services now, and how things can be done better, so that national strategies can be translated to Frontline improvements.

The policy context in Northern Ireland

There have been recent developments in responding to the needs of people with autism in Northern Ireland. An Independent Review of Autism Services was undertaken during 2007. It reported that, while some improvements had been made regionally for children and young people with autism, further work was required to develop services for adolescents and adults.

Recommendations from the review 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, and the development of the DHSSPS' Autistic spectrum disorder (ASD) strategic action plan 2008/09 – 2010/11' (15). The action plan was also informed by other reviews, including the Bamford 'Autistic spectrum disorders' recommendations (16), the Bamford 'Equal lives' report (24) and 'Families matter: Supporting families in Northern Ireland' (18).

The plan highlights the need for a person-centred and whole-life approach to effective provision of health and social care services, which include the statutory, private, voluntary and community sectors. It is linked to a care pathway approach, which is designed to enhance early recognition, integrated assessment, diagnosis, evidence-based interventions and ongoing support.

The action plan is 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.

A multi-disciplinary Regional Autistic Spectrum Disorder Network group was set up to take forward and implement the action plan, and commenced work in April 2009. It is linked to the broader implementation of 'Delivering the Bamford vision' (19). Autism sub-groups have been established to take forward a range of workstreams, and developments will be informed by the evidence base of good practice for diagnosis, assessment and service provision.

A range of developments have been identified and include:

- the provision of local specialist teams
- a health & social care trust-led local integrated network linked to the leadership provided by the Regional ASD Group
- reduced waiting times
- the development of a regionally agreed multi-disciplinary care pathway and standards for early referral, assessment, diagnosis and support
- performance improvements
- improvements in standardised data collection and service mapping
- training and education to support professionals and families in early identification of signs of autism
- communication and information for families.

The Autism Act (Northern Ireland) 2011, implemented in May 2011, primarily covers two areas for development. First, the Act requires changes to the Disability Discrimination Act 1995 to include people with autism. The definition of disability will be amended so that criteria for measuring disability will include 'taking part in normal social interaction; or forming social relationships', thereby promoting access to services and benefits. Second, the Act requires the Northern Ireland government to implement a cross-departmental autism strategy (led by the DHSSPS), 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.

Further reading

- [Further information on the Regional ASD Network developments](#)
- Department of Health, Social Services and Public Safety (2009) Autistic spectrum disorder strategic action plan 2008/09 – 2010/11, Belfast: Department of Health, Social Services and Public Safety.
- Maginnis, K. (2008) Independent review of autism services, Belfast: Department of Health, Social Services and Public Safety.

Awareness raising and diagnosis

In this section we explore:

- why social care staff need to know more about autism
- how they can go about learning more
- the role of social care staff in making sure that people with autism can get a diagnosis
- how social care workers can support someone when they have been diagnosed.

'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.' *Adult with autism (20)*

Raising awareness

'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.'

(Adult with autism (7))

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. Work is under way to change this.

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 really 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 is key, and should:

- cover how to recognise autism, and how to make reasonable adjustments to accommodate people with autism
- be delivered efficiently - this could mean sharing training between organisations, or including autism in general equalities training, for some staff
- be delivered in detail for those conducting assessments, those working directly with people with autism and the managers of these people **(21, 11)**
- alter behaviour and practice among key professionals - it isn't enough to attend training but then carry on as before
- include input from people with autism and their families **(11)**

- cover awareness raising about Asperger's Syndrome and high-functioning autism - the lack of support offered to people with autism of these types (7) means that staff may have less awareness and experience here, so more needs to be done to redress the balance.

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.

One aspect of awareness raising that came up in our research was that of mutual misunderstanding (7). People without autism lack understanding of the condition, but some people with autism find the language and customs of the 'neurotypical'* world perplexing and forbidding, 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 (22), for there to be a meeting of minds, it is up to those who do not have impaired social communication (such as difficulties with empathy or guessing other people's intentions and feelings) - the neurotypical people in society - to make more adjustments (22).

Making these adjustments, and spreading awareness about autism, is vital in making sure that people are directed to the right sources of support - be that a diagnostic service, social services, support groups or a disability employment adviser. If more people know more about autism, support can be targeted more promptly and more effectively (23), with the possibility of better outcomes, and with less battling for services and support on the part of people with autism and their families.

* Neurotypical is used by many people with autism to describe those without the condition.

Diagnosis

Diagnosis ... that's the very, very beginning ... you're not always given a lot of information about what that diagnosis actually means. (7)

Diagnosing autism is a task for medical professionals, and Fulfilling and Rewarding Lives (10) and the 'Autism strategic action plan for Northern Ireland' (24) both plan improvements to medical diagnostic pathways, for adults and children. A well-informed social care workforce has a vital role to play, however, 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.

Getting a diagnosis of autism, especially as an adult, can be hard: four out of five people in our research found obtaining a diagnosis in adulthood either difficult or not possible (7). For some, a diagnosis of autism can lead to discrimination (41), but there are some key benefits:

- A diagnosis helps explain, to the person, their family and friends, and the wider public, what had previously been unknown or misunderstood.
- It can help shape an improved support package, as long as this is not done in a mechanistic, 'someone has this, they get this' (7) way.
- It avoids the problems of misdiagnosis, as faced by people with autism wrongly thought to have a mental health problem, for example.
- It can assist with accessing services and benefits, such as a Disabled Students' Allowance (25).

The social care workforce therefore needs to know how to go about making 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 timely, appropriate referrals can be made, which waste the time of neither people with autism nor professionals.

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

- A diagnosis, Fulfilling and Rewarding Lives makes clear, is a reason to assess people's social care needs, rather than exclude them from assessment (10, 11), as has happened in the past for people with Asperger's Syndrome or high-functioning autism.
- Diagnoses can indicate what a person might benefit from, but should not be any more than a guide. The person remains an individual, for whom their autism is but one of the facets that makes them who they are.
- 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 (7).
- 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.
- Information-sharing between NHS-based diagnostic services, and local authority/trust, private 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.

Accessibility and acceptability

In this section we explore:

- how to conduct assessments with people with autism
- what can make services hard to access
- how to make sure that social care services are accessible and acceptable for people with autism, from a commissioning and a Frontline point of view
- the role of specialist autism services.

Assessments

'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.'

(Adult with autism (7))

Offering an assessment to someone who has, or may have, autism is a proactive duty for local authorities/trusts. In the past, many adults with autism, particularly those with Asperger's Syndrome or high-functioning autism, did not have assessments (26), and often those assessments that were carried out were in areas offering limited training in how to assess people with autism (27).

Assessing the social care needs of someone with autism should be done by a person with sufficient training and experience, and the forms that they use need to be sufficiently well constructed to capture the sometimes subtle needs that people with autism can have.

People with autism can find assessments perplexing. While this in part relates to the nature of autism, many carers we spoke to also found assessment processes confusing (50), so the issue is one that services should address.

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 link to getting 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 is prompted at every stage of the cooking process

- may find the concept on which Fair Access to Care Services (FACS)* eligibility decisions are made, namely what would happen if needs were not met (9), overly abstract
- have often been let down by services in the past
- may have spent a great deal of time and effort developing ways to cloak their difficulties
- have family members/carers who mediate the outside world and compensate for someone's difficulties
- may come from cultures in which people are reluctant to acknowledge developmental disabilities, particularly when there is a strong genetic link. Some cultural differences will also cloak some difficulties, for example by being less reliant on the use of body language.

Preparing in advance and flexibility towards the person with autism may help the assessment process capture the right information. If you are conducting an assessment with someone with autism (28):

- be clear about your role right 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. This can be difficult given performance targets, but it ought to be a reasonable adjustment that you can make
- 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
- focus on the person's strengths and achievements.

You might also want to ask yourself (28):

- 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 after-shave?
- 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 that 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 (28):

- 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** (ADHD)
- 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. The needs of siblings should be considered.

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 if the person with autism is also a parent or carer, and if so, how their autism affects how they care for the other person.

It is important to consider the impact of autism 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.

For more tips on communicating generally with people with autism, see the Making services accessible and acceptable - Frontline staff subsection.

* In Northern Ireland, the DHSSPS 'Circular HSC (ECCU) 1/2010: Care management, provision of care and charging guidance' applies (not FACS).

Further reading

- Saeki, M. and Powell, A. (2008) *Social care: Assessment of need for adults with an autism spectrum disorder*, Birmingham and London: British Association of Social Workers and National Autistic Society.
- Social Care Institute for Excellence (2010) '**Fair access to care services**', SCIE Guide 33, London: Social Care Institute for Excellence.

Barriers

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

(Adult with autism (7))

In our **Introduction**, we looked at some of the general barriers to accessing services experienced by people with autism. Here, we explore in more detail some of the challenges people with autism face when trying to access social care.

Contacting social care services, particularly for the first time, can be problematic. When offering services, information or support to people with autism, 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 people with autism 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 if they do, not denied a service (7)
- services should continuously examine their processes and language, to identify what might form a barrier to people with autism
- 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 – unhelpful telephone operators, long periods on hold, 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.

Our research showed that many people with autism have little contact with social care, living in their own or their families' properties, and seeking assistance from friends and family, rather than professionals (7). This may reflect people who are living independent lives, and who do not need whatever services have to offer. Many, though, will be people trying to cope alone, or relying wholly on family members, because services are either inaccessible or they see them as inadequate at meeting their needs.

This can be exacerbated by the fear some people with autism have of other people's perceptions, of not being accepted, or not being believed. Some people we spoke to said that people did not think that they deserved help, because they appeared so normal on the surface (7). This links to the frustration of people with autism being expected to do things that are simply beyond them because there is no **obvious**

reason why they can't. Other people are concerned about the stigma involved in having a label or receiving social care services; this can be heightened for people who put a lot of effort into appearing neurotypical or who have been bullied extensively.

We came across people for whom services were only accessible because a single individual was helpful. 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 (7). Turning individual islands of accessibility into something more systematic would help make things better for people with autism.

Too many services, when they are offered, are not suitable. Designed either for people with learning disabilities or for people with mental health problems, they lack the specialist knowledge and experience to effectively support people with autism. Learning disability day centres, for instance, will sometimes change activities for the summer months, which can cause people with autism anxiety (20), and in general they rely on a lot of group activities, which may not work for some people with autism.

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 (7). Often, people are placed in expensive residential or hospital provision, where they can become detached from their family and community.

Making services accessible and acceptable - commissioners

'I asked why they did not contact me on the phone I had explicitly told them about - we can't do that we don't have the staff - so, what do you do for blind people? - we have a bill reading service - so you ring them - yes - so why don't you provide for the mentally ill?'

(Adult with autism (7))

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. Some of them will also be of benefit in healthcare, education and employment settings, as well as in mainstream services such as leisure centres and libraries.

Commissioners should try to ensure that (29):

- 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; outreach should be flexible, such as being able to provide short, intensive work during a crisis
- 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 family carers in service design and delivery
- explicitly include autism within key documents such as equalities policies, Joint Strategic Needs Assessments* and local housing plans, as examples
- use the Disability Discrimination Act 2005 requirements 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 in other parts of the UK) to support people with autism to make decisions
- make use of the Mental Health and Learning Disability Standard Contract*, which explicitly covers autism. This is a legally binding document covering all NHS-commissioned services for the named client groups, and can help ensure that services are meeting their obligations to people with autism.

One approach is to provide services in a local, or regional, centre of excellence (30), a 'one-stop shop' for people with autism, 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 (65).

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 in muted tones, and fixtures and fittings that can withstand damage

- good-quality supported living and 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 (66)
- additional security measures or telecare if people are deemed vulnerable or have high levels of anxiety
- all backed with well-trained and well-motivated staff, offering a mixed package of practical and emotional support, as and when people need it. 67

With specialist provision, regional cooperation may be needed. More locally, though, 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 (22).

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

* Not applicable in Northern Ireland.

Making services accessible and acceptable - Frontline staff

The techniques of working with adults with Asperger's Syndrome require a degree of anticipation, rehearsal and self-regulation. They do not just come naturally to people. They have to be learnt and applied. (27)

To ensure that services are accessible to people with autism, it helps to bear certain things in mind in day-to-day work. The most important is that a person's autism will never be more than one part of what makes them who they are. That said, some general points can be made. In order to build good working relationships with people with autism (28):

- be patient: people with autism can be challenging, can appear rude, and can miss appointments
- 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.

Planning in advance can make it more likely that whatever the person with autism is involved in will run smoothly. A person's likes can be catered for, and potential triggers identified and avoided, for example by going out shopping at quieter times. When planning a day, or an activity:

- Include the person with autism 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, 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 with autism can achieve (31).
- 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 (32).
- 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 approach if you're causing distress. If a person with autism would be overwhelmed on a given day by being asked to do something, then it might that day need to be done for them.
- Make use of special interests, and use wall-charts or timings to provide structure (32).
- Remember that people with autism will have comprehension that varies from day to day, hour to hour.

Whether planning or engaged in an activity, good communication is vital. Consider the following when communicating with people with autism (33, 28):

- Be conscious of the environment in which you are communicating. Lights, sounds, animals or crowds can all be distracting. Sometimes, this can be unpredictable but often it can be predicted that, for example, a supermarket will be bright, noisy and busy.
- 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.
- Use closed questions more than you might normally do.
- Be consistent, across your own communication, between 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. Putting the photographs or objects in a box afterwards can help establish that the activity is finished.
- 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.
- The point at which to communicate about something can be important. Communicating well in advance of an activity will help some people mentally

prepare for it. For others with autism, 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. If someone becomes upset, for example, when asked to move into a new room, you need to know why. Is it because they have not understood you, are they wary of the bright lights in the new room or do they find the transition from one room to another difficult? Autism is just the context, albeit one you need to know well.

As discussed earlier in the context of assessments, a lot of these communication tips are applicable to all social care users, and are things staff ought to be able to do. A lot of support to people with autism could be improved by the consistent application of general good practice principles.

Further reading

Thorpe, P. (2009) *Caring for adults with autism*, London: National Autistic Society.

Two common approaches

Among many frameworks for supporting people with autism, two interventions are common at a service level. We list them here not as a recommendation for any individual, as different approaches may work more or less effectively for different people, but for information purposes.

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, and therefore the importance of getting to know a person in real depth. Applying SPELL principles can support people across the autistic spectrum, and can complement other approaches such as 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 successfully their home, educational and professional lives, by addressing environmental obstacles, and by working with people to adapt their behaviours. There is a focus on structured learning and skill development.

Several tools are used to assist the communication of people with autism, many involving visual devices. PECS - Picture Exchange Communication System - involves swapping pictures for a desired activity or object, and labelling involves attaching a symbol to the thing it represents. Some people with autism use Makaton - a communication system that combines words, gestures and a small core vocabulary of signs.

Further reading

- [SPELL](#)
- [TEACCH](#)

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. Fulfilling and Rewarding Lives(10) and its attendant guidance (11) (and the DHSSPS action plan for Northern Ireland (24)), 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 (14). Autism is a complex condition, and sometimes people will be well served only by people with well-developed expertise.

Whether specialist services are in place, be that a care management service or provision such as day care or supported living, will depend ultimately on local need and commissioning priorities. But Fulfilling and Rewarding Lives, despite the emphasis on awareness raising and generalised improvement, stresses that specialist services have a 'pivotal role' (10) in improving outcomes for people with autism, despite the current patchiness of their provision. Specialist services, especially multi-disciplinary ones, do seem to hold out the promise of better outcomes (6), and Fulfilling and Rewarding Lives promotes autism-specific bodies for the delivery of services, such as specialist autism teams and autism partnership boards (10). This message is also stressed in the DHSSPS action plan for Northern Ireland (24).

When we spoke to people, the message was clear that specialist autism services are more accessible than general social care provision (7). The National Audit Office study, 'Supporting adults with autism through adulthood' (23), goes further: specialist teams can improve outcomes, and have the potential to save significant sums of money. This is looked at in more detail in the Early intervention and prevention section.

One example is the Prospects employment service, run by the National Autistic Society. It costs Prospects more per head to place someone in work than it costs general disability employment services (23), but the jobs last longer, carry greater satisfaction for employer and employee and lead to long-lasting benefits to people's incomes and sense of self-worth (23).

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

- [Prospects employment service](#)

Joint working

In this section we explore:

- social care as part of a wider service landscape
- how social care professionals can collaborate on service planning
- how local areas can judge their progress.

The service landscape

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 any mainstream service or support they should opt to use.

And while social care can be hard to access, so too can these other service areas (7). This can mean that some people with autism, worn out by the struggle, access nothing, and so miss out on the chances of cross-referral to other services they need. 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 difficulties faced by people with autism in getting social care need to be considered alongside the problems experienced in accessing work, healthcare, education and money.

The complexity and inaccessibility of the benefits system was a major theme in the research we carried out (7). People with autism can be anxious about applying for, and perhaps being refused, benefits such as Disability Living Allowance, which can fail properly to consider issues facing people with autism. The forms involved can be forbiddingly complicated, and the office spaces that house benefits staff can be bright and noisy (23). Not applying, however, can lead to financial disadvantage.

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

- bright, noisy, loud healthcare settings
- lack of awareness among health professionals
- diagnostic overshadowing - everything being put down to a person's autism
- difficulties people with autism have in communicating - for example explaining where the pain is
- poor awareness of autism in mental health services, which tend to have a recovery focus, which is unhelpful to people with autism
- 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, for those with autism as for most people, can be important in developing self-esteem and ending benefits dependency. Some key points are worth considering:

- With the right support, people with autism 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 (61).
- Often this is because many people with autism find interviews difficult: the concept of selling oneself, or putting a positive gloss on one's experiences can be wholly alien for some people with autism.
- Reasonable adjustments can be made: work trials can give a more accurate picture of someone's skills than interviews, for example.
- Job descriptions needs to be looked at. 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 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.

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 Making services accessible and acceptable - commissioners, we described some of the main housing needs of people with autism. However, because many people with autism 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.

In the education field, 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 (25), but quiet periods in the Freshers' Fair and web-based courses are examples of reasonable adjustments that can be made. Others include:

- pastoral support from trained staff
- autism awareness training for staff
- information provided in clear and literal language, including in exams
- providing extra time for individual pieces of work, and for courses as a whole
- support around organising time
- extra support around exam time and other periods when routines change
- making specific accommodation arrangements, taking into account sensory sensitivities (52).

As social care opens itself up to people with high-functioning autism and Asperger's Syndrome more, links with the higher education sector are likely to grow.

The mechanisms for joint working

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, especially those with Asperger's Syndrome or high-functioning autism, can fall between the gaps in social care provision, and sometimes receive little or no social care support, until perhaps their needs escalate to crisis point. More collaborative efforts, at strategic and operational level (35), can prevent this happening (36).

Locally, the key strategic mechanism for this is the Joint Strategic Needs Assessment*. Currently, these are produced by Local Strategic Partnerships and led by directors of public health. The Joint Strategic Needs Assessment in each area will, pending legislation, become the responsibility of the local Health and Wellbeing Boards, which will bring together local authorities, general practice commissioners, other public and voluntary sector bodies and - via Healthwatch - user and carer representatives.

Fulfilling and Rewarding Livesplaces the Joint Strategic Needs Assessment at the heart of joined-up planning for people with autism (10). The first task for Joint Strategic Needs Assessments 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 (11)
- 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 on the agenda of all relevant planning groups, and 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 and user-led organisations, and promote the involvement of people with autism and their carers in service design and delivery
- promote localised, non-residential provision (23), which will involve 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 clear 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 (but does not insist) that autism planning can be done by local autism partnership boards, which bring together people with autism, their carers and advocates, service providers and statutory commissioners to look in more detail at how services for people with autism can be improved (10). Another proposed option is an autism subgroup attached to learning disability or mental health partnership boards. The strategy also calls for an expanded role for community and autism user-led organisations in leading on this joint working (10).

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 at not just social care, but also links with employment, housing and other mainstream services, and at locally determined priorities.

How joint working on autism is developing at a regional level varies from area to area, but as central government direction reduces and pilot developments such as Community Budgets take shape, local autism bodies have the opportunity to influence provision in meaningful ways. In some regions, the needs of people with autism are included in general themes such as employment or housing in Joint Improvement Partnership plans, drawn up by local authority leads, strategic health partners and other key agencies*. In other regions, Joint Improvement Plans take a specific autism focus in their delivery mechanisms. Each region has a Department of Health deputy regional director who can advise on how autism developments are making progress. The deputy regional directors, alongside the regional bodies they support, will also identify local autism specialist services that may be able to build their capacity (10).

* 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 (37). Mechanisms for joint working are a focus of the DHSSPS strategic action plan for autism 2008/09–2010/2011 (15).

Measuring achievements

Our approach to evaluating progress towards [Fulfilling and Rewarding Lives] is based on tangible quality outcomes - visible and measurable indications of whether the vision is being realised. (10)

The government has released a document, 'Fulfilling and rewarding lives: The strategy for adults with autism: Evaluating progress'(10), in which it sets out the outcome measures* against which local areas can test how well they are meeting the aims of the autism strategy.

There are seven quality outcomes. Adults with autism 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 access personal budgets
- no longer be inappropriately managed in the criminal justice system
- be satisfied with local services, as will their families and carers
- 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.

Measuring progress against these outcomes and ambitions is not mandatory, but the intention of government is that local people with autism and their families work together with local organisations to test how far services have come, and how far they have yet to go, towards achieving them. The Department of Health supplies a self-assessment document to help local bodies record and measure their progress.

The government acknowledges that, in most areas, achieving these outcomes is a long-term goal. It therefore sets out 10 steps that local areas should take (again, they are not compulsory) to help them make progress (10):

- Appoint a local autism lead.
- Include autism in all key procedures.
- Collect and collate relevant data about adults with autism.
- Develop an integrated commissioning plan for adults with autism.
- Develop a training plan for Frontline staff.
- Map local employment services that support adults with autism.
- Map local voluntary groups that support adults with autism.
- Involve adults with autism, and their families and carers in service design and planning.
- Implement a staff survey about working with adults with autism.
- Learn from and share best practice.

* The performance measurements and outcomes in 'Fulfilling and rewarding lives: The strategy for adults with autism: Evaluating progress' do not apply to Northern Ireland. These are being developed by the Regional ASD Network as part of the strategic action plan for autism (15).

Further reading

- Department of Health (2010) Fulfilling and rewarding lives: The strategy for adults with autism: Evaluating progress, London: Department of Health.
- Department of Health (2011) Fulfilling and rewarding lives: The strategy for adults with autism in England and statutory advice: Essential quality outcomes for local self-assessment framework, London: Department of Health.

Transitions

In this section we explore:

- working together to get the transition from children's to adults' services right
- the transitions people with autism go through as they and their family get older.

Getting transition right

'If anybody should look at anything, they should look at that transition.

(Residential home manager (7))

The transition from children's to adults' social care, problematic for many groups, can be particularly difficult for people with autism. At present, 70 per cent of children with autism identified in the special educational needs system have statements of special educational needs, and are thus entitled to transition planning from Year 9 (14 years of age). A similar proportion of local areas have multi-disciplinary transition protocols (11). Despite this, and despite a general consensus that people need personalised, holistic and ambitious transition plans (10), many young people with autism need to be served better by the transition process.

They face the same problems as other groups during transition (7), 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 on their now-adult family member.

In addition, 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 chance of falling through the gaps in adult services for people with high-functioning autism and Asperger's Syndrome.
- Adult life and expectations, including the world of personal relationships, can carry new challenges for people with autism (6).
- There is limited provision of further education options for people with autism, especially those who display challenging behaviour (7).

Furthermore, if transition for people with autism goes badly, they can be stuck in poor-quality services, and have lives that are not as independent as they ought to be (36).

During transition, there needs to be (38):

- 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
- better information given to families as young people approach transition
- better communication between adults' and children's services. Some local areas are placing Children with Disabilities staff within adult teams to promote joint working; others are adopting a 'single trusted contact' model. Research is needed into whether approaches like this can be effective in improving outcomes
- an opportunity for people placed out-of-area to return home, should they wish
- training in autism for transition staff, including staff working in child and adolescent mental health services, supporting young people with autism and mental health problems to access adult mental health support
- attention paid to the needs of young people with autism who display challenging behaviour (39)
- autism training for Connexions workers, and better links between Connexions and social care staff
- differentiation in assessments between support needs and education needs, so that people are not put on academically limited courses due to their communication difficulties
- an underlying assumption, including in specialist schools, that young people with autism, including those with challenging behaviour, can and should lead full lives of their own choosing.

In England, transition planning is being addressed in 'Support and aspiration: A new approach to special educational needs and disability' (40), with proposals for a unified assessment, and an 'Education, Health and Care Plan', covering social care, education, health and support into employment, which runs until a person is 25. There is a strong emphasis also on professionals having much higher aspirations for children with disabilities (40), building on the messages of 'Aiming high for disabled children' (41) and the Transition Support Programme. Although the Transition Support Programme ends in 2011, local areas will have developed greater knowledge and expertise in transition as a result.

The focus in 'Support and aspiration' on reducing the number of people who have a statement of special educational needs may mean that some people with autism fall outside of the transition planning process, although having a statement is not the only route to support through transition (11).

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 on the identification and assessment of special educational needs' (42) and a supplement to the Code of Practice issued in 2005 (43). A Task Group on Autism was set up in November 2000 to make recommendations on educational provision for children and young people with autism, and recommended that transition processes be more

inclusive of young people and their families, cover all aspects of a young person's life and promote the better sharing of information (44). Furthermore, a priority for action of the DHSSPS strategic action plan is the development of multi-disciplinary, multi-agency approaches to transition (24).

A government inter-departmental group comprising of the Department of Education, the Department for Employment and Learning and the DHSSPS 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 transitions planning and provides a wide range of actions to make improvements in moving across the spectrum of service provision (45).

Further reading

- Department for Education (2011) Support and aspiration: A new approach to special educational needs and disability: A consultation, Green Paper, Cm 8027, London: The Stationery Office.
- Department of Education Northern Ireland (2002) The education of children and young people with autistic spectrum disorders: Report of the Task Group on autism, Belfast: Department of Education Northern Ireland.
- Department of Education, Department for Employment and Learning and Department of Health, Social Services and Public Safety (2006) Report of the Transitions Inter-Departmental Working Group, Belfast: Department of Education, Department for Employment and Learning and Department of Health, Social Services and Public Safety.
- Social Care Institute for Excellence (2011) 'Challenging behaviour: a guide for family carers on getting the right support for teenagers', At a Glance 39, London: Social Care Institute for Excellence.

Growing older

Autism was not included in the main European or American classification of diseases manuals until the late 1970s and early 1980s, with Asperger's Syndrome included even later (46). 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. Even now, gaining a diagnosis for older people can be hard, because it is difficult to draw up an accurate picture of early years' development without traceable records or the input of parents (46). 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' (47).

It also means that there is little research into the needs of older people with autism. A recent study (47) indicated that older people with autism were socially isolated, and had difficulties with sustaining employment and relationships. It concluded that 'the problems that manifest themselves in youth are destined to become lifelong companions',

although it identified fewer behavioural difficulties among older people with autism than younger ones (47).

Diagnosing older people with autism is important, however, so that they can benefit as others do from the greater understanding and access to services that a diagnosis can bring (see Awareness raising and diagnosis section). People face some key transitions as they age, such as retirement and bereavements, and it is important that people receive appropriate support.

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 people with autism 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 substantial care to people with often very high needs (23). 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.

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 (48), to address the concerns of both the person with autism 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.

Older people with autism are less likely to access physical healthcare on their own and often enter the healthcare system at the point of severe health decline. This can result in expensive nursing home placements or hospitalisations. They are also less likely to ask for adaptations to their property or home help.

Early intervention and prevention

In this section we explore:

- how small amounts of practical and social support can benefit people with autism, and have the potential to mean that more intensive services are needed less often
- the role of social support for people with autism.

‘Perhaps if they had been helped a bit earlier it wouldn't have got so bad.’

(A mother of a woman with autism (7))

Early intervention and eligibility

Some of the difficulties faced by people with autism could be addressed or reduced if low-level, often relatively inexpensive services were provided promptly (30). This notion of early intervention* is, however, often hampered by what people with autism sometimes experience as inflexible and reactive services. This inflexibility is often linked to people's experience of Fair Access to Care Services (FACS) or DHSSPS 'Care management, provision of care and charging guidance' eligibility criteria (9, 49). FACS criteria measure whether the risk to a person's independence would be at low, moderate, substantial or critical risk if services were not provided (9). Most local authorities only provide services to people whose needs are in the substantial or critical bands (9), which tends to militate against the provision of early intervention services.

However, skilled commissioning of preventative services** and effective use of the provisions within FACS (or the DHSSPS 'Care management, provision of care and charging guidance') that promote preventative support can be used. The revised guidance on applying FACS makes it clear that staff should:

- have prevention and early intervention at the front of their minds when carrying out their work
- work with individuals and their support networks whose situation may deteriorate, and where early intervention could prevent or delay the need for social care support
- provide interventions to address specific barriers preventing individuals achieving their goals
- help people to access short-term health or technological support or re-ablement services, to promote independence and reduce risks
- use predictive tools that can identify and target individuals who could benefit from signposting and early decision making
- identify sources of support for individuals and carers on the edge of needing social care, or who have low or moderate social care needs, to help them retain control over their lives and achieve the outcomes they want (50).

The focus in Fulfilling and Rewarding Lives(10) and the 'Autism strategic action plan for Northern Ireland' (24) 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. The insistence in Fulfilling and Rewarding Lives that a diagnosis of any form of autism must be a reason to offer an assessment, rather than deny one, does mean that people with high-functioning autism or Asperger's Syndrome have at least overcome one hurdle to getting the support they need, even if they still have to have eligible needs under FACS. The expectations under 'Putting people first' that local areas will provide a universal information and advice service (42) should also mean that people with autism can be pointed in the right direction for accessing help.

* We are taking early intervention here to mean the timely provision of services to people with autism. We do not mean interventions that aim to militate or remove the effects of the condition.

** Again, by preventative, we do not mean services that aim to prevent autism. We mean services that aim to prevent social care needs from escalating.

Intervening early

'My AS [Asperger's Syndrome] son ... had to be removed at one point from the home and put in an emergency residential placement for 18 months because he has not had access to appropriate mental health services.'

(A parent of someone with autism (7))

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's 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 decent 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 carers and families (23). For many, these small amounts of practical support will then be sufficient to help them manage in society (7). Many people with autism choose to spend personal budgets on just this sort of care (10). Support 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 (7). National Audit Office research (23) indicates that supporting more people with high-functioning autism and Asperger's Syndrome - those most often excluded from services - quickly becomes cost neutral, and can potentially lead to long-term savings. These savings come from higher tax incomes and reduced benefits payments as people are supported into employment, and reduced mental health and criminal justice costs as people are supported before they reach crisis points in their lives.

Supporting an extra 4 per cent of people with high-functioning autism in a local area could make the service carrying out that support cost neutral. If 8 per cent more people were supported, savings could total £67 million (23). There is a challenge to be met here for commissioners and policy-makers: the bodies that would need to spend more - most likely local authorities/trusts - are not those set to benefit most heavily from any savings - mental health trusts, the Exchequer and the criminal justice system.

The National Audit Office report highlights, therefore, the potential benefits, for outcomes and budgets, of specialist care management teams for people with high-functioning autism and Asperger's Syndrome (23). Although only a small amount, and quite new, evidence so far suggests that people with high-functioning autism and Asperger's Syndrome who have access to these teams (23):

- 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, there are fewer people with high-functioning autism in residential or in-patient 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, be that high-functioning autism, or autism linked with learning disabilities and complex behaviours, are often placed in expensive residential care
- it costs about £60,000 a year less to support a person with autism in their own home than place them in residential care (23)
- placements are often far removed from a person's family and community
- out-of-area placements are relatively more expensive than local ones (52) and are infrequently used for positive reasons such as proximity to loved ones
- out-of-area placements commonly reflect a lack of local provision or expertise, and are often associated with poorer access to specialist healthcare (23)
- money spent on out-of-area placements is money that cannot be spent developing local expertise (6), 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 (23), although provision of them is patchy.

Social support

Social interaction is difficult for people with autism. For many people with autism, therefore, training in social skills, or 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 the workplace; in isolation it can be less effective.

Social support can come in many forms and as always what constitutes the right sort of social support will vary from person to person. Our research showed people were fairly consistent in wanting support with social activities, but more varied in exactly how they socialised currently, and what else they wanted by way of social activities (7).

People with autism most commonly socialise with family members and friends, but we found that the next most common arena for socialising was online (7). As a medium in which people can exert more control over the timing, pace and flow of both giving and receiving information, interacting online may have real benefits for many people with autism.

Difficulties with public transport and low incomes can make socialising problematic (20). Other barriers to successful social interaction for many of the people to whom we spoke included a lack of suitable activities, not feeling accepted and being worried about other people's perceptions (7). For some, this led to a desire for autism-specific social spaces, perhaps structured around certain themes or interests (30). Others, however, expressed disquiet about groups targeted at people with autism, and stressed the value of ordinary activities, and asserted their right to be accepted within them (7). Still others found buddy schemes very helpful. Here, an identified person or 'buddy' supports them as they negotiate new situations. Other people with autism had benefited from mentoring and life coaching.

The range of preferences is important to note, as it again highlights the heterogeneity of needs that people with autism have. In all social support schemes, however, it is worth noting:

- 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 the support staff.
- People need to have a choice in who supports them, and be able to state their preferences over common interests.
- Schemes need to have confident, consistent, well-trained staff. They need to have 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 anxious, or be able to anticipate difficulties.

Personalising services

In this section we explore:

- the potential benefits of personalisation for people with autism
- the barriers to enjoying these benefits
- how to overcome the barriers at an organisational and Frontline level
- work as a route to choice and control.

A personalised approach based on an understanding of the nature of the condition and individual need, sensitively supported by local specialised expertise and multi-agency collaboration, would appear to be more likely to be associated with increased satisfaction and a better outcome for adults with ASC. (6)

The benefits of personalisation for people with autism

'[A] request I had, was this man who wanted a car, a man with autism, who was phobic about buses, couldn't go on buses. The mother had her own health problems, dad had very significant ones as well ... He had a brother who had come up from (city) who wanted to take him camping but couldn't do it because there was no transport. And buying a car actually meant that he could travel without taxis, save a thousand of pounds of money in about six months on taxi fares. He had a PA and did go camping several times which was the breaks he had, he could also go to his day activities when he chose to because he was able to get to and from them as he chose to do it - and all those things were covered by buying a car.'

(Service manager, social services (7))

Personalisation can have a positive impact on the lives of people who use it (53). 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 (36).

People with autism often have complex and highly individual needs that are hard to accommodate in services delivered to groups of people (31). A diagnosis of autism is arguably only as useful as the personalised, suitable services to which it then leads, and while there is a shortage of really strong evidence about which services work best for people with autism, indications are that specialised and individualised services achieve better outcomes (6). Some people with autism require flexible services completely tailored to them as individuals for their needs to be met effectively. Large, shared residential homes can be inappropriate for people who have complex social, communication and sensory needs (30), and people with autism require, therefore, a wider range of personalised housing options.

Giving people with autism and their support network choices over who supports them creates an opportunity to get exactly the right person for the job, including perhaps a family member or a friend, who knows the person really well.

The barriers to the benefits

Of the people with autism with whom we spoke, those who used a personal budget were generally positive about the personalisation of their social care, with over 80 per cent of them viewing the budget as working well, or well 'to some extent' (7). However, very few people we surveyed (11) had access to a personal budget, and as local authorities continue to roll them out, there is a challenge to be met in ensuring that people with autism take advantage.

Various barriers to personalisation were cited by people in our research (7):

- the bureaucracy involved in applying for something about which they knew relatively little: 'I expected 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. This was not necessarily scepticism about personalisation as a concept, but a concern that, as switching to a personal budget might involve a review or re-assessment of needs, it would be used as an opportunity to reduce support
- 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 book-keeping 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 that people with autism may have in conveying their needs accurately, unless supported to do so by knowledgeable people and well-designed tools.
- Personalisation may lead to the closure of some services, which people with autism may find disconcerting, and the micro-commissioned services that come in their place are yet to establish themselves among people with autism as able to meet their needs (23).

- Personalisation may therefore lead to greater social isolation and vulnerability (6).
- People with autism, who find the subtleties of human interaction confusing, may find some issues inherent in employing personal assistants difficult. Maintaining appropriate boundaries, particularly if employing family or friends, may be particularly challenging.
- There may be more gaps in service delivery due to sickness/staff training, when people have just one or two people who support them. People should plan what to do in this event.
- Professionals sometimes lack sufficient knowledge of personalised options, or of autism, to make personalisation work for people with autism (20).
- The world of person-centred planning uses vague and metaphorical terms such as health passports, dreams, doughnuts and circles.
- 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.

Person-centred working can also be hampered by inflexibility within systems, poor communication between agencies and with users and families and by ever-tighter financial restrictions (54).

How to overcome the barriers at an organisational level

'I've worked with guys who needed very intensive transitions and multiple visits getting staff to build positive relationships with them where they are before they come to us, introducing all kinds of augmentative communication tools to try and ease things... At the other end I've worked with people who could not tolerate knowing something was going to happen but it not happening and working to very very short transition deadlines, one guy came to us ... his parents brought him and the first he knew that he was moving was when he got out the car at our place, but that worked ok for him because that's what he could handle.'

(Manager, residential home (7))

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, including 'Putting people first' (51) and Think Local, Act Personal(13), call for a universal offer of advice and support in finding appropriate assistance, so personalisation in its broadest sense ought to have something to offer even those people with autism who do not have eligible needs under Fair Access to Care System. And 'Fulfilling and rewarding lives(10), as we have seen, will bring more people with autism into the social care system, and give them the chance of a personalised package.

Resource Allocation Systems* need to allow for high-quality, flexible support, and should cover the costs of brokerage (55) and allow for staff and organisations with expertise in autism to be purchased if necessary (56). The local leadership that the strategy sets up will need to try to make sure that this happens (11), and also that Resource Allocation System-based provision is not so slow to set up as to cause undue anxiety to people with autism.

Local leaders also need to set out where people with high-functioning autism or Asperger's Syndrome, who have often been denied services, get the personalised support they need under the strategy. Personalisation has been cited by the government as the means to stop people falling between the gaps in services (11), and local areas will need to choose which social work team people who have autism, but no learning disability or significant mental health problem, go to in order to receive social care, whether delivered by a personal budget or in more traditional ways.

The Right to Control pilots, currently being led by the Office for Disability Issues (57), aim to unify various funding streams, to create personal budgets that are more flexible because they cover more of a person's needs. This is potentially beneficial to all social care users, but by bringing together several sources of funding into one place, people with autism, who may have complex needs and difficulty making sense of bureaucratic systems, stand to be particularly well served (58).

For some of the bureaucratic hurdles involved in personalising one's support to be overcome, advocacy and independent brokerage will need to be available to people with autism (23), 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 good quality and varied, and to include well-trained personal assistants who understand autism, and who can understand them (30).

Developing a local structure for personalised services can best be done in partnership with people with autism and their families, in line with the recommendations of Fulfilling and Rewarding Lives(10) and the 'Autism strategic action plan for Northern Ireland' (19). User-led organisations can also help develop acceptable services for people with autism to purchase (59).

Options about the different ways in which personalised services can be accessed need to be provided. People with autism are likely to benefit from some more managed forms of personalised budgets, such as:

- personal trusts, in which money is held by people close to the user
- direct payments, which have a longer history of enabling choice and control for people
- individual service funds, in which a service holds a budget on behalf of, and for the sole use of, a person with autism
- care-managed budgets, in which a person's budget is overseen for them by care managers (56).

Local advocacy services with an understanding of people with autism need to be available to ensure that people with autism 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 in other parts of the UK) as a way of ensuring that people with autism are properly and legally supported to make decisions.

Personalisation has potential for people with autism. However, it is not so well established as a beneficial method of service delivery that its merits should be taken for granted. By its nature, it ought not to be introduced as a blanket policy, and how well it works needs to remain the subject of expert scrutiny (6).

* Resource Allocation Systems are not applicable in Northern Ireland.

Further reading

- Social Care Institute for Excellence (2009) Mental Capacity Act resource, London: Social Care Institute for Excellence.

Work as a route to choice and control

‘There is not a silver bullet or magic wand but, insofar as there is anything approaching one, it has to be around employment because ... it partly addresses the money problem and the mental health issues.’

(Richard Bacon MP (35))

Only 15 per cent of people with autism are in full-time employment (35), so too many are financially and socially excluded by not working (10). Employment can be a powerful mechanism in promoting control over an individual's life. People with autism, with appropriate support, and if supported by the benefits system, can really benefit from working (55). Prospects, the National Autistic Society's specialist employment service, has success in finding work for people with autism (23, 55) (people with autism, once they are used to a job, are often diligent, good at paying attention to detail and unlikely to move from job to job) (35). 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 people with autism is slight (6), suggesting that more needs to be done to change employer and colleague perceptions

about autism (10). Better autism awareness for Department for Work and Pensions staff would benefit people with autism seeking job opportunities (59).

Further reading

- HM Government (2011) Valuing people now - employment: Supported employment and job coaching: Best practice guidelines, London: HM Government.
- [Work Programme](#)
- [Access to Work](#)

Carers

In this section we explore:

- the needs of those caring for people with autism, and how those needs can be met.

The situation for carers

‘Over the years you just get drained with the constant rejection.’

(Mother of someone with autism (7))

Many carers of people with autism face significant daily challenges in supporting the person 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 at times, can be considerable. Where such pressures exist, they are typically lifelong, and can persist whether or not the person with autism lives with their carer or not. Some people with autism will not see that they need support, even if their families are under strain, and that lack of awareness of the pressures their carers may be under can itself add to those pressures (6). Some people with autism can block support services designed for their carer, for example by not letting people into the house. Carers' benefits sometimes feel like scant recompense (7), especially in those families where there is more than one person with autism.

What our research into accessing services for people with autism revealed is that these pressures are too often coupled for carers with the pressure of battling with organisations for what is needed or wanted (7). This battle applies to services for the person with autism, but perhaps even more so to services for carers themselves (20). The job of caring for someone with autism can act as a powerful barrier to life and employment options for carers (62). It is a situation that leads some carers to the edge of mental wellbeing, and some into mental ill-health.

Of carers we spoke to, only three per cent found gaining access to carers' services easy (7). Many had not even tried, citing a sense of it not being worth having yet more struggles with authorities, for what was perceived as little likely benefit (7). Many carers reserved their energies for seeking services for the person with autism they support, as this, for many, was challenge enough. Carers we spoke to found access to social activities, diagnosis, education, housing, employment and social services hard to come by for the person with autism for whom they care (7).

Accessing these services often requires real doggedness by carers and family members. When services are accessed, carers often feel that the people employed in them do not know enough about autism (23). Many carers, parents especially, 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 (28). The development of personalised services makes some carers fear they will be marginalised further (7), or burdened with extra tasks and responsibilities.

Given its genetic element, it is important to remember at all times that carers may also have autism.

How best to support carers

‘I think involving the families is incredibly important ... I think if you find a good family unit for goodness sake incorporate it because that will save everybody a lot of time and energy.’

(Parent of someone with autism (7))

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 receive one (7). A diagnosis of any form of autism should act as a trigger to offer a carer's assessment to all those actively supporting the diagnosed individual. Carers' assessments can be offered even if the person with autism has refused an assessment for themselves.

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 (7)
- recognise the incredibly in-depth, detailed knowledge that carers have (35)
- 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 (31)
- 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 a person with autism 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
- plan early with families for what may happen, to help allay these concerns.

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 person with autism and the outside world, such as answering all telephone calls, arranging appointments and taking care of correspondence.

The need for clear communication with people with autism is mirrored by the need to communicate clearly with carers, and avoid professional jargon, which can act as a barrier to collaborative working (31). This matters, because only by liaising with families can professionals develop a 'full, vibrant and functional picture of the individual with autism' (63).

Carers and family members quickly become expert in the person with autism they support. They often become hugely well informed in autism more generally, and many carers also become experts in how social care systems operate (7). This makes them ideal partners to work with services, at individual and organisational levels, to create better services not only for the person with autism they support, but also for the wider autistic population. Carers for 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, be it by advising local authorities/trusts over the provision of services, setting up mutually supportive group meetings or using the power of collective complaints to address poor access to services for people with autism (7).

Personalised services for the person with autism can offer carers a greater say in how things are run, but can also increase their workload, adding book-keeping and employment law to the knowledge and skills required for already hard-pressed people. Carers undertaking these tasks need proper support that suits them, be that training in how to do them, or quality brokerage services who can do the tasks instead.

Fulfilling and Rewarding Lives does not cover the separate needs of carers in great detail, but its calls for the proper application of existing policy and legislation to people with autism extend to carers, who would benefit from organisations simply applying carers legislation promptly and effectively (10). The revised Carers Strategy for England, 'Recognised, valued and supported' (64) emphasises the expertise that carers have, but stresses too that they should be entitled to dignity, financial wellbeing and a life beyond caring. Other key aspects of 'Recognised, valued and supported' are:

- 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*
- 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.

* Joint Strategic Needs Assessments are not applicable in Northern Ireland.

Further reading

- Department of Health (2010) Recognised, valued and supported: Next steps for the Carers Strategy, London: Department of Health.

Policy context: an overview of policy and legislation affecting people with autism

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)

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.
- Government ratification of the UN Convention on the Rights of Disabled People (2009)
- Office for Disability Studies (2009) Independent living: A cross-government strategy about independent living for disabled people, London: Office for Disability Studies.
- Department of Health (2010) Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care, London: Department of Health.
- Department of Health (2010) Recognised, valued and supported: Next steps for the Carers Strategy, London: Department of Health.
- Department of Health (2010) A vision for adult social care: Capable communities and active citizens, London: Department of Health.
- Department of Health (2010) Equity and excellence: Liberating the NHS, White Paper, Cm 7881, London: Department of Health.
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Underpinning research: the University of Sussex Practice Enquiry

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January 2011

This practice enquiry, which ran from December 2009 to July 2010, was the third strand of a SCIE project sponsored by the Department of Health (DH), in order to inform and support their strategy for adults with ASC. The key question that led to the practice enquiry was:

How far [do] current services and strategies support or hinder people with ASC to live independently and to what extent [do] current processes exclude people with ASC by denying social care support to enable them to access services and mainstream provision? (Commissioning Brief, September 2009)

The evaluation sought to:

- invite and consider a range of views about the provision of services to support independent living for adults with ASC, from people with ASC receiving services, those who have had difficulty accessing support, their carers and other stakeholders
- identify views on issues of access to assessment processes
- identify views on what assessments achieve for people with ASC and their carers and on provision of service
- identify the policy and practice challenges which may affect access to support and experience of provision of services
- identify areas of 'good practice' as perceived by people who use services and carers and other stakeholders in access to and experience of provision of services
- provide recommendations that may inform future good practice in the provision of services for adults with ASC.

The methods included:

- two online surveys: aimed at adults with ASC and carers, hosted by NAS, and designed to gather quantitative and qualitative data
- survey follow-up: where participants agreed, the online surveys were followed up in more depth via email or telephone, depending on the participant's preference
- service provider questionnaires: issued to track the names of the service providers that respondents had given to the online surveys and others
- participation group involvement: NAS put a set of questions to two of their participation groups for people with ASC and higher levels of communication need
- three sites provided qualitative data from face-to-face interviews with people with ASC, carers and service providers in rural and urban areas of England.

Improving access to social care for people with autism

This guide is primarily for frontline, managerial and commissioning staff in the social care sector. Most sections are relevant for all of these groups, while some are targeted at either people working on the front line or more senior staff.

This is made clear in the section titles. The guide is built upon *Access to social care for adults with autistic spectrum conditions*, a practice enquiry conducted with people with autism and their families by the University of Sussex, on behalf of SCIE. It is informed too by SCIE Research Briefing 32: *Access to social care and support for adults with autistic spectrum conditions (ASC)*, as well as drawing upon other work and opinion identified by SCIE staff as relevant. It makes extensive reference to Fulfilling and Rewarding Lives, the government's autism strategy, and its supporting documents.

The guide was drawn up with the help of an Advisory Group, which included people on the autistic spectrum, their carers, representatives of ADASS, Autism London, and the National Autistic Society, and academics.

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