



Improving access to social care for adults with autism

Key messages

- Greater autism awareness among social care workers needs to go hand-in-hand with in-depth knowledge of the individual with autism.
- Better understanding of autism in the social care sector can help people get a diagnosis of autism, and get timely, appropriate support after diagnosis.
- Staff need to make adjustments in their work, planning and communication with people with autism, and with each other, so that services can be more accessible.
- Commissioners of services need to be flexible and collaborative in meeting the needs of people with autism, especially those whose behaviour challenges services, and those with Asperger's Syndrome or high-functioning autism.
- People with autism need particularly good support during significant life changes.
- Personalised approaches can benefit people with autism, and professionals need to support them and their families to make the most of them.
- Support with social interaction and everyday living tasks can address some of the needs people with autism have, at relatively low cost.
- Carers of people with autism typically know them extremely well. Professionals should offer carers support in their own right, and work with them to provide the best possible services for people with autism.

Introduction

People with autism often see the world around them as chaotic and complicated, where people communicate in confusing ways, and places like supermarkets, streets and hospitals can be forbiddingly unpredictable. It is not a world designed by or for people with autism. Social care staff have an important role to play in supporting people with autism to engage with the wider world, but also in leading the effort to make the wider world adjust to and accommodate people with autism.

This At a glance briefing looks at the key messages from SCIE's practice guide *Improving access to social care for adults with autism*. The briefing sets out how social care workers can understand people with autism better, and tailor services to their specific needs.

‘Understanding the condition is no substitute for understanding the person.’

Department of Health

Awareness raising and diagnosis

Social care staff need to improve their awareness of autism, to help them identify when someone may have it, and properly support someone who does. Training in how to identify autism, and how to make adjustments to accommodate the needs of people with autism, are key to addressing this.

Social care workers have a vital role in referring people for a diagnosis of autism. Some people can feel stigmatised by such a diagnosis, but it can help in accessing benefits and services. When people are diagnosed, social care staff need to offer advice, information and the right package of support. This requires good links between social care staff and health professionals carrying out diagnoses.

While awareness of autism is important, social care workers need to get to know the personality and needs of each person with the condition to ensure the most effective support.

Fulfilling and Rewarding Lives

Fulfilling and Rewarding Lives is the governmental strategy for improving outcomes for adults with autism in England. It urges a culture shift to respect the equality and human rights of people with autism, and it seeks improved:

- 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 is backed by statutory guidance, *Implementing Fulfilling and Rewarding Lives*. Together they call on public bodies, including social care organisations, to meet their duties to people with autism by consistently applying to them social care, health and equality legislation, and policies such as Valuing People Now, and Think Local, Act Personal.

The strategy and guidance make clear that any autism diagnosis, including Asperger's Syndrome or high-functioning autism, should trigger an assessment for services, as do equivalent plans in Northern Ireland .

Acceptability and accessibility

Social care needs to become more approachable to people with autism, from assessment through to the provision and review of services. This means adjusting assessment processes so people with autism can engage with them, perhaps by allowing more time or by communicating as the

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person wishes – for example by email. Busy meetings might not be ideal to plan and review services; alternatives include the person sharing their thoughts by video, or in a smaller pre-meeting. Support should take place in calm environments, set up to maximise the involvement of the person with autism. The knowledge carers have of a person with autism can be helpful in understanding their preferences.

Supporting someone with autism will involve being aware of autism-related factors such as difficulties with social interactions and

‘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

communication, or sensitivities to noise or light. However, much of what helps make services approachable to people with autism is key to all good social care: clear communication; being reliable and consistent; getting to know people as individuals; and being accepting of them.

Specialist autism services – such as employment services, day provision, or care management – are often more approachable to people with autism, and should form part of a locally available range of services. Mainstream services should also be able to support people with autism, as should services that support people to live with their families or independently, rather than in residential provision.

The SPELL framework

Whatever the service, well-tested approaches to working with people with autism, such as SPELL, can help.

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

- **STRUCTURE** to making the world more predictable and manageable.
- **POSITIVE** approaches and expectations to build people's strengths.
- **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 so support is consistent and predictable.

Joint working

Joint working matters, 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

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mainstream services, and all of these can be, like social care, hard to access.

The key tool for joining up support in English authorities is the local Joint Strategic Needs Assessment (JSNA), in which all public sector bodies come together to map and meet the needs of the local population, including people with autism. The local lead commissioner for autism, a role mandated by Fulfilling and Rewarding Lives, must ensure the JSNA is based on good data about the needs, accommodation and demographics of the local autism population.

In Northern Ireland a multi-disciplinary Regional Autistic Spectrum Disorder Network group (RASDN) has been set up to implement the autism action plan.

Transitions

Many people with autism experience difficulties moving from children's to adults' services. Staffing inconsistencies, fewer resources within adult social care, and going from the structure of school to the greater freedoms of adulthood can all be unsettling. Services should:

- involve people with autism and their families in transition planning, and respect their preferences
- improve communication between adults' and children's services, and between services and families
- train transition, careers, and child and adolescent mental health staff in autism

- work to the presumption that young people with autism, including those with challenging behaviour, can develop academically and lead full, self-determined lives.

As people with autism age, other important transitions, such as changing needs and the death of parents, can occur. Planning should whenever possible take place in advance of changes to the family situation, to address the concerns of the person with autism and their carers. Emergency plans, detailing the support needed if care arrangements break down, can ease anxiety, and lessen the likelihood of emergency residential placements.

‘Perhaps if [she] had been helped a bit earlier it wouldn’t have got so bad.’

A mother of a woman with autism

Early intervention and prevention

Some difficulties faced by people with autism can be addressed by low-level, often relatively inexpensive services, particularly if provided promptly at the point of diagnosis. People with high-functioning autism or Asperger’s Syndrome may find that advice, help with tasks like bill-paying and form-filling, and support with social skills can help them cope and prevent social isolation. People with autism and complex learning disabilities or challenging behaviour may benefit from intensive support at home, coupled with decent respite services, thus avoiding expensive residential care.

Social interaction is difficult for people with autism. Training in social skills, or the opportunity to engage in comfortable social situations, can prevent many from feeling isolated and unable to cope. What constitutes the right social support will vary from person to person.

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Personalising services

People with autism often have complex needs that are hard to accommodate in group settings, and require flexible, individually-tailored services. Giving people with autism and their carers choice over who works with them means they can be supported by someone who really understands them.

We found people had concerns about personalisation, such as added bureaucracy and a fear of financial exploitation. There are challenges in ensuring people with autism get the best from personalisation:

- Self-assessment forms and Resource Allocation Systems (RASs) need to capture the nuances of autism, as people with autism may have difficulty conveying their needs accurately.
- People with autism, who find the subtleties of human interaction confusing, may find some issues inherent in employing personal assistants challenging.
- There may be inconsistencies in support due to staff sickness or training, when people employ just one or two staff.
- Person-centred planning uses vague, metaphorical terms like health passports, doughnuts and circles.

‘Giving people with autism and their carers choice over who works with them means they can be supported by someone who really understands them.’

RASs (not applicable in Northern Ireland) need to allow for high-quality support from staff with expertise in autism, and should cover brokerage costs. Workers should provide information about more managed forms of personalised budgets, as people with autism might benefit from:

- direct payments
- personal trusts, in which money is held by people close to the user
- individual service funds, in which a service holds a budget 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.

Support with employment, often an important route to choice and control, should also be considered.

Carers

Many carers of people with autism face significant daily challenges supporting people who can see the world differently, appear unresponsive, or even be destructive. Carers are often an expert about the person with autism they support and may become well-informed in autism generally. Carers for people with a recent diagnosis, however, may benefit from information and advice on autism.

Carers often require real determination to access services, either for themselves or for the person

with autism. A carer’s assessment is the first step in accessing their own support, and upon a diagnosis of any form of autism, professionals should encourage all those supporting the diagnosed individual to have a carer’s assessment.

Professionals can help carers by:

- taking on board the experience and detailed knowledge they have about the person with autism
- understanding the love, and investment of time and emotion over many years, that most carers bring to discussions about the person with autism
- respecting the different views a person with autism and their carer may have
- recognising that carers may be anxious about the future, when they are no longer around, and planning early with families for what may happen.

‘Many carers of people with autism face significant daily challenges supporting people who can see the world differently, or appear unresponsive.’

Key references

Taylor, I. and Marrable, T. (2011) *Access to social care for adults with autistic spectrum conditions*, London: SCIE and University of Sussex

Mills, R. and Francis, J. (2010) *Access to social care and support for adults with autistic spectrum conditions*, Research Briefing 32, London: Social Care Institute for Excellence

Department of Health (2010) *Fulfilling and rewarding lives: The strategy for adults with autism in England*, London: Department of Health

National Audit Office (2009) *Supporting people with autism through adulthood*, London: The Stationery Office

DHSSPS (2009) *Autistic Spectrum Disorder Strategic Action Plan 2008/09–2010/11*. Belfast, DHSSPS

Useful information

SCIE Guide 43 *Improving access to social care for adults with autism*, London: Social Care Institute for Excellence

National Autistic Society website
www.autism.org.uk

Think Local, Act Personal (2011)
www.thinklocalactpersonal.org.uk

Valuing People Now (2009)
www.dh.gov.uk
London: Department of Health

Department of Health (2010) *Fulfilling and rewarding lives: The strategy for adults with autism in England*, London: Department of Health

Department of Health (2010) *Implementing Fulfilling and Rewarding Lives: Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy*, London: Department of Health

National Audit Office (2009) *Supporting people with autism through adulthood*, London: The Stationery Office

Maginnis, K. (2008) *Independent Review of Autism Services*, London: The Stationery Office

The Autism Act (Northern Ireland) 2011, Belfast: Department of Health, Social Services and Public Safety

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**Social Care
Institute for Excellence**
Fifth floor
2–4 Cockspur Street
London SW1Y 5BH

tel: 020 7024 7650
fax: 020 7024 7651
www.scie.org.uk

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