

At a glance 21

Personalisation briefing



February 2010

Implications for people with autistic spectrum conditions and their family carers

Key messages

Personalisation for people with autistic spectrum conditions (ASC) means:

- treating people with ASC as individuals who have control over their lives
- understanding that traditional service settings may not be the best option for people with ASC
- ensuring that the person with an ASC takes as much control as possible over their support and life design
- understanding how a person's routines and rituals affect their life – this is only possible through high quality support planning
- ensuring that all staff supporting the person are trained in ASC and that training is refreshed regularly
- enabling the person to develop meaningful relationships with others, to reduce safeguarding issues and empowering the person to sustain relationships
- ensuring that people with ASC and their families have good access to information to help with decision making.

This At a Glance briefing examines the implications of the personalisation agenda for people with autistic spectrum conditions.

Personalisation means thinking about care and support services in an entirely different way. This means starting with the person as an individual with strengths, preferences and aspirations and putting them at the centre of the process of identifying their needs and making choices about how and when they are supported to live their lives. It requires a significant transformation of adult social care so that all systems, processes, staff and services are geared up to put people first.

The traditional service-led approach has often meant that people with autistic spectrum conditions have not received the right help at the right time and have been unable to shape the kind of support they need. Personalisation is about giving people much more choice and control over their lives in all social care settings and is far wider than simply giving personal budgets to people eligible for council funding. Personalisation means addressing the needs and aspirations of whole communities to ensure everyone has access to the right information, advice and advocacy to make good decisions about the support they need. It means ensuring that people have wider choice in how their needs are met and are able to access universal services such as transport, leisure and education, housing and health services. It means people are given opportunities for employment regardless of age or disability.



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Implications for people with ASC and their families

The personalisation agenda is largely a positive development for people with autistic spectrum conditions (ASC). People with ASC have hugely varied needs, and should therefore be well served by services truly tailored to an individual, with all of his/her personal needs and preferences. In the National Audit Office's publication *Supporting people with autism through adulthood*, 82 per cent of third sector organisations said that personal budgets would allow for more direct contact with the person; 78 per cent said that support would be more tailored to the individual and 77 per cent said there would be greater choice. Having more choice and control over your life improves your quality of life, so personalisation should be a positive experience for many people with ASC.

The assessment process

The community care assessment process, including self assessment, can be bewildering for people with ASC. The terms and eligibility bands used in the assessments are complex and may be highly confusing. The assessment process should therefore be adapted to be more accessible for people with ASC (Saeki & Powell, 2008). Staff assisting people with ASC to complete these forms should have autism awareness training.

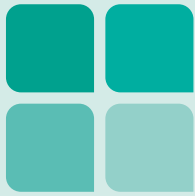
Eligibility criteria for Fair Access to Care can often automatically exclude people with higher functioning autism and Asperger's Syndrome, but changes brought about by personalisation should benefit this group, by making them entitled at least to better signposting and advice services.

Health action plans should be completed for all people with ASC to identify associated health needs. This will allow better support planning and will ensure the person is able to access all the funding streams they are entitled to.

Person-centred planning

Excellent person-centred planning (PCP) and support planning is essential to the personalisation process for people with ASC. This can be undertaken by self advocates, families, PCP facilitators or brokers. Quite simple methods of planning work well with people with ASC, for example the One Page Profile (the learning community for person-centred practices).

People with ASC and their families should be involved in person-centred planning in ways that are meaningful to them. Using approaches such as TEACCH (treatment and education of autistic and related communication handicapped children), PECS (picture exchange communication system), Total Communication and person-centred thinking is important to allow people who communicate in alternative ways to share their views. The terminology used in person-centred thinking may not be comprehensible, as people with ASC often understand language by its literal meaning. For example, 'circles', 'dreams' and 'donuts' are terms often used in person-centred thinking and may be misunderstood by people with ASC. There is a resource called the *Autism Minibook* (Helen Sanderson Associates and The National Autistic Society, 2009) which



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Case study: Andrew's story

Andrew is 32 years old. He is intelligent, motivated, charming and focused.

In April 2008 Andrew was diagnosed with Asperger's Syndrome. In partnership with his social worker, Andrew decided to apply for self-directed support and he received his indicative budget in September 2009. He started working with a broker to develop his plan.

Andrew outlined his support plan by identifying the changes he wanted in his life and the activities he wished to pursue. Discussions led to the development of his ideas and the introduction of new opportunities. Andrew used a pictorial schedule to plan his ideal week and preferred activities which included: skiing lessons, dog walking classes, independent living classes, sponsoring a player from his favourite ice hockey team, a photography course and many more. Andrew's budget was approved in November 2009.

Sharing his story with others at various events and being able to access the people, the places and the support he needs have increased Andrew's self esteem, motivation and zest for life. Andrew recently commented that he would never have felt this confident a few months ago and his mother stated how beneficial brokerage was in assisting Andrew and the family through the support planning process.

has suggested alternative terminology to improve accessibility to people with ASC.

'Circle' meetings involving a lot of people are often used in person-centred planning, but tend not to be appropriate for people with ASC. This is because people with ASC often find large groups of people stressful. One-to-one work may be

better, where the person's views can be found out, and this information can be fed into the plans.

Planning with people with ASC should happen in low arousal settings. This means quiet rooms without too many people, with calm lighting and not too many distractions. People with ASC often have sensory sensitivities and may not be able to concentrate or participate in an environment with too much sensory information.

Following these recommendations will support the improvement of quality support planning, and will enable the person's special interests, routines and rituals to be incorporated into the plan.

Young people and transition

Transition planning for students in special education starts in year 9 and year 10 at Transition Reviews. These plans are the basis for an adult life. Families need to have accessible information during this process and the means to understand what their options are when their child leaves formal education. The We Can Dream project (Foundation for People with Learning Disabilities and National Autistic Society,) supported four young people embarking upon adult life through the person centred planning process, and helped them design a life using individual budgets. The project showed the importance of being supported by creative staff committed to the ideals of personalisation, and that low professional expectations about people with ASC, and limited training for staff, can be significant barriers that need to be overcome.

Families whose children attend mainstream school have voiced concerns that transition reviews only take place in special educational settings therefore they are in a position of



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'catch up' when their child reaches 18 years old.

Change can be extremely stressful for people with ASC, making careful transition planning extremely important. Careful planning, management and preparation time must be considered as a priority.

Employing personal assistants or providers

Employing personal assistants or providers can be really beneficial to individuals with ASC. Traditionally, staff are recruited by an agency/provider and therefore not recruited for the person but for the service. Personalisation gives the person and their family and friends the opportunity to recruit staff that have specific skills and personalities that suit working with people with ASC. The support plan should reflect this. Some people with ASC are employing family and close friends, allowing the people who often know them best to be able to provide ongoing, high quality support.

Things to be aware of when employing your own staff

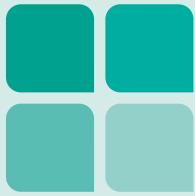
- Lone working can be unsustainable for both the person with ASC and the supporter. Single person settings can be too intensive for a person with ASC.
- Specialist autism training, regularly updated and refreshed, is needed for supporters. The support plan must reflect this cost.
- Providers need to meet the specialist requirements of the support plan within the costs of the person's resource allocation.

- People with ASC do not need to understand fully the responsibilities of being an employer, but they may need to be supported to understand that they cannot, for example, break off a working relationship without what employment law would recognise as a good reason. Employment experts, user-led organisations and recruitment professionals may help to empower and support people with ASC.
- Time to build relationships with supporters is often essential and should be reflected in the support plan.
- All staff recruited should have contracts with the person with ASC or their representative and people.

Safeguarding

There are specific safeguarding issues that need to be considered when planning personalised support for people with ASC:

- People with ASC may find it difficult to communicate their wishes and understand what other people are telling them. Even though they can be articulate and give the impression that they understand everything being said, they may not understand at all.
- They may have a wish to please others and to conform. This leaves many people vulnerable when dealing with others.
- They can trust too easily and may not have a full understanding of what is going on. This can lead to financial vulnerability if they are handling their own budget.
- People with ASC often have difficulty with social understanding, meaning that relationship boundaries may be problematic.



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If a person with ASC employs a close family friend or becomes friends with their support worker, the boundary between 'friend' and 'paid support' becomes blurred. Many people with ASC need support to understand the difference between a friend and a paid supporter, and how to interact with them. One-to-one support can often be too intensive for both the person and their supporter, especially when repetitive and challenging behaviours are present.

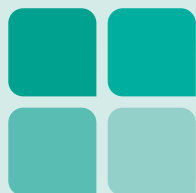
People who lack capacity in certain areas may need advocacy. The provision of advocacy is good practice, as it ensures someone independent is part of the person's relationship network, which can reduce the risk of a person with ASC using personalised support being mistreated. A further safeguard is that under the Mental Capacity Act (2005) local authorities have a responsibility to be satisfied that anyone making decisions on behalf of a person who lacks capacity in any given area – including managing their personal budget - is acting in a way that protects the best interests of the person receiving support.

Managing the money

People with ASC and their families do not have to manage the money they receive from their personal budget themselves. Many people initially thought this was the case and found the situation very daunting. Some people with ASC find it hard to deal with money and have few budgeting skills. This is often true when someone has been diagnosed as having ASC later on in life and so has missed out on the support needed for them to learn about money.

There are different ways to manage the budget:

- Direct payment
- Direct payment to agent,
- Direct payment to Trust
- broker
- Individual Service Fund (provider)
- care managed



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Acknowledgements

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Useful websites

www.nationalbrokeragenetwork.org.uk

www.autism.org.uk-The National Autistic Society

www.helensandersonassociates.co.uk

www.Shop4support.co.uk

www.Incontrol.org.uk

www.learningdisabilites.org.uk (FPLD)

www.dh.gov.uk-Putting People First, personalisation toolkit,

www.ncil.org.uk-National Centre for Independent Living

Further information

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

Saeki and Powell (2008) *Social care assessment of need* London: The National Autistic Society

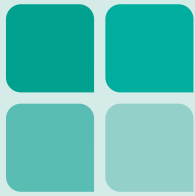
Helen Sanderson Associates and The National Autistic Society (2009) *Autism minibook*
London: HAS publications

Foundation for People with Learning Disabilities and The National Autistic Society (2009)
We can dream London: FPLD publications

SPELL Framework –The National Autistic Society (2003) *Approaches to Autism, an easy to use guide to many and varied approaches to autism 5th edition* London: National Autistic Society

Mental Capacity Act 2005 London: Department of Health

Department of Health (2007) *Putting People First – A shared vision and commitment to the transformation of adult social care* London: Department of Health



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In its report *Personalisation: a rough guide*, the Social Care Institute for Excellence (SCIE) tells the personalisation story so far – exploring what it is, where the idea came from and where it sits within wider public service reform. It is freely available online at www.scie.org.uk

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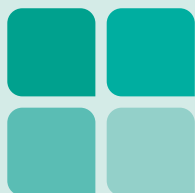
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