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# Access to social care and support for adults with autistic spectrum conditions (ASC)

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## Key messages

- Outcomes for adults with autistic spectrum conditions (ASC) are generally poor. Many people with ASC experience unemployment; mental and physical ill-health, discrimination and social exclusion.

- The evidence base evaluating services for people with ASC is weak.

- There are significant variations between individual adults with ASC, so that 'one size fits all' practices are ineffective. Evidence suggests that adults with ASC benefit from services, e.g. employment and care, which adopt autism-specific approaches delivered via specialist, multi-disciplinary teams.

- Access to social care is often problematic, compounded by the complexities of the autistic spectrum, by other health-related difficulties, the impact of eligibility criteria and the lack of specific services for adults with ASC.

- The transition period of moving from children's services to those for adults is problematic.

- Individuals with ASC and additional intellectual disability generally have fewer problems in accessing support, often provided by local learning disability services. However these services may struggle to support individuals with additional or complex needs.

- The condition and needs of more 'able' individuals with ASC may go unrecognised or be misdiagnosed.

- More information is needed about individuals with ASC and additional sensory processing differences to enable them to access services.

- Too few health or social care staff have sufficient expertise or experience for assessing or working with people with ASC.

- Research is needed to investigate the lower take-up of social care among people from minority ethnic and cultural groups, women and older people with ASC.

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# Introduction

The term 'autistic spectrum conditions' (ASC) is used throughout this briefing to describe what were previously called autistic spectrum disorders (ASD) and is the one now preferred by the Department of Health in England. However, the term is seldom used in the scientific literature or in other countries and for this reason is potentially confusing and problematic.

Autism spectrum conditions are present from birth or very early life and are classified in the International Classification of Diseases (ICD-10) as pervasive developmental disorders (PDD). They include childhood autism, Asperger's syndrome, atypical autism and PDD unspecified. In practice many of these conditions may overlap with other disorders.[1] Affecting more boys than girls, although the prevalence in girls is said to be underestimated,[2,3] these conditions are neurobiological and characterised by significant impairments in instinctive social behaviour, reciprocal communication and a restricted or repetitive repertoire of behaviours and interests. These 'core' features will affect the person's ability to anticipate the thoughts and actions of others and predict day-to-day outcomes on the basis of normally occurring social cues. This lack of ability to anticipate and predict leads to high levels of stress and difficulties in relating to others. Such difficulties may be accompanied by other neurological or psychiatric conditions that impact on behaviour and functioning and on access to services and support. Such conditions include, but are not limited to, disorders affecting sensory processing, anxiety, depression and mood, seizures and other medical problems. These co-morbid conditions are often treatable in the same way as in the non-ASC or so called, 'neurotypical'* population.

Individuals with ASC have widely differing levels of IQ and social functioning. The causes are unknown but genetic factors are important.[4]

*'Neurotypical' is the preferred term used by many with ASC to describe people without ASC.

An absence of neat dividing lines between the different forms of the condition and its variability can comprise a perplexing juxtaposition of ability and disability and an absence of usual development alongside the presence of the unusual. It is this complex and often fascinating presentation, the unusual combination of high-level skills alongside deficits, that is the cause of much misunderstanding of the nature of ASC, affecting decisions about help and support.

Autistic spectrum conditions affect around one in one hundred of the general population[5] but people with such conditions are highly heterogeneous. A range of provision is required. The nature of the spectrum means that not all will require intensive services but most will need at least some level of understanding and support at some stage in their lives.[6] Diagnosis is very important but it should be borne in mind that no two individuals will be completely alike and what helps one person will not necessarily help another. Assessment of need to go alongside diagnosis is therefore crucial.[7] Diagnosis should therefore be seen as a process leading to helpful action and not merely acquiring a label.

# What is the issue?

Autism has been described as a 'hidden' or 'invisible' disability.[8] Although historically associated with intellectual disability, it is now thought that most people with ASC will be within the normal range of IQ.[5] Whatever the label used, the complexity of the autistic spectrum often renders it easier to misunderstand than it is to recognise. These difficulties, which can make access to services problematic, are further complicated by the generic nature of many services and the fragmented way they view and respond to ASC.[9] It is not uncommon for individuals with ASC to be seeking support from several different agencies at the same time. They may discover they do not meet criteria for eligibility or may only receive help in crisis situations.[10] The National Audit Office (NAO) maintains considerable cost savings

could be made if there were better informed and more timely interventions.[9]

The Autism Act 2009 and attendant strategy are responding to the large numbers of adults living with autism who have not so far received adequate recognition and support. Historically, services for this group were provided by specialised voluntary agencies that were in most cases started by parents of individuals with ASC and in the main related to educational and residential services. As a result, specialised approaches for working with individuals with ASC, for example TEACCH and SPELL,[11] began to emerge. Over time, other providers from the private and voluntary sector became involved but again these were primarily related to educational and residential services; only recently have more individualised approaches begun to materialise. This growth in provision was against a backdrop of hospital closures and a shift to community care, even though some service models were as congregate and distant from local communities as the institutions they replaced. Few services for adults with ASC have so far been evaluated but many of the former residents of hospitals with ASC fared poorly in new community services, which were ill-equipped to support them safely.[12]

## Developing services

An accreditation scheme, set up by the National Autistic Society (NAS) with funds from the Department of Health, sought to define specialised autism practice through the application of autism specific standards and peer review of services, although these standards have so far not been evaluated. There is now general agreement of the need for specific or at least informed services for people on the autistic spectrum and that traditional services such as residential and day services have largely failed to meet their needs.

Studies of adults suggest that for a substantial number the outcome is poor:[13] adults with ASC lead more restricted lives, are less independent and experience higher unemployment, stress, health problems, sleep disorders, bullying, discrimination, neglect and vulnerability.[14,15] Little is known about the demographics and the needs or experiences of older adults on the spectrum and those who are ageing. Some will come into contact with the criminal justice system as victims, witnesses or offenders.[16] The core features of the condition are known to be resistant to change over time, even with intervention.[17] Additionally, there is increased risk of other behavioural and medical problems.[18]

In adults, disruption to routine or lifestyle may cause or exacerbate mental health difficulties[19] and a number of such adults will present to health or social care professionals for the first time in adulthood.[20] For some people, the nature of difficulties and their severity may change as they age and the more disabling effects of the condition may improve. The reasons for these changes are unclear. Some of the more able people will develop their own strategies for coping[21–24] but in general the characteristics present in childhood persist into adulthood.[25,26]

With the possible exception of some communication-based behavioural interventions, the evidence for specific forms of early intervention is not yet compelling.[27] Additionally, despite there being no specific drug treatment for the core features of ASC, studies highlight concerns about side effects and misuse of psychotropic medication to control the symptoms.[28–30] There is also a concern about the potential for abuse of vulnerable adults in the social care system: the increasing personalisation of social care may fail to offer protection and may in some cases heighten isolation and vulnerability.[31]

Despite the high costs associated with social care for adults with ASC,[32] there has been relatively little systematic evaluation of services.[33] Consequently, the evidence base for choosing between types of services is weak.

## Why is this important?

The Department of Health strategy[34] aims to support people with ASC to live independently as equal and included citizens, as described by human rights legislation and the Disability Discrimination Act 1995.[35] According to the Department of Health, this means ensuring that programmes aimed at improving care and transforming care services address the needs of people with ASC and that mainstream public services become more inclusive of people with ASC. As with other forms of disability, a reasonable adjustment under the Disability Discrimination Act should mean that it is more likely that individuals with ASC are free from discrimination and able to live more productive and fulfilled lives and make a contribution to the community. Due in part to the heterogeneity of people with ASC, it is not always apparent what form this reasonable adjustment should take but the evidence suggests that attention to the sensory environment is important.

The provision of appropriate social care requires understanding of a number of aspects of the person and their circumstances. These include:

- age
- type and level of disability
- sex
- family circumstances
- social relationships
- vulnerability
- geography
- access issues
- racial and cultural factors.

The level of understanding of ASC and expertise available locally will also be influential in the development of services.[9] All of the above variables will impact on the nature of services needed and the take-up of those services.[36] Pilot projects and experimental services are useful but a service cannot simply be replicated because it seems to work in one location with one set of users, unless there is an understanding of the underlying variables.

## The policy context

The past two decades have seen a major shift towards services provided in ordinary community settings rather than in large hospitals, although until recently virtually no account was taken of individuals with ASC of higher ability. The last five years have seen a change in policy towards recognition of the whole autistic spectrum culminating in the Autism Act 2009 and the required strategy, prepared by government to examine the following aspects:

- health – ensuring that the NHS provides full and equal access to good quality healthcare, including diagnosis and post-diagnostic follow-up.

- social inclusion – ensuring that services are fully inclusive, such as independent living and housing, citizenship, meaningful activity, social support and outreach, e.g. befriending, advocacy, social skills training and other ASC specific services.

- employment – ensuring that adults with ASC have meaningful engagements with employment including employment support and financial security.

- choice and control – ensuring that people have real choice and control over their lives and services.

- training – ensuring that people working with adults with ASC have appropriate training.

This strategy is in line with current social policies: guidance will follow during 2010. It remains an open question as to how much will be resourced or whether the cost neutral improvements indicated by the NAO will be achieved.

For adults with more complex ASC and challenging behaviour, the period 1990–2005 saw little tangible progress, particularly in the capacity of local services to make effective social care available.[37,38] It is sobering that the recommendations of Mansell's original 1993 report,[37] 'that local specialist services should be developed and expanded to support good mainstream practice as well as directly serve a small number of people with the most challenging needs', remain just as relevant today. With inadequate local provision, commissioners still send people to high-cost, low-value services a long way from home. Moreover, 14 years later Mansell pointed out that, for people with complex needs and behaviour living in special hospitals or prisons, local health or social care agencies were reluctant to meet the bill for a local package of care, constituting a significant barrier of dubious legality.[39]

The Royal College of Psychiatrists shared these concerns and found that the development of appropriate services and eligibility for people with ASC depended heavily on the ability of professionals to identify the condition and make an informed diagnosis and assessment of need.[40] A Royal College of Psychiatrists working group examined the role of out-of-area treatment placements for working age adults without learning disabilities but with complex and severe psychiatric disorder; including ASC. The working group's findings highlight particular areas of concern including the range of clinical conditions provided for; geographical location of services; availability of appropriate and responsive services; commissioning arrangements; organisation of services; information monitoring and follow-up; and strategic planning. The working group blamed health services reorganisation for compromising the development of specialised expertise and capacity. In their view, the result has been to limit the development of a range of locally based alternatives, which can seem more difficult and expensive to offer than out-of-area residential treatment.[40]

Numerous policy circulars and guidance documents have been issued in recent years, aimed at transforming the basis of social care in general and, in some cases, services for people with ASC specifically.[41–51] To varying degrees, each has emphasised a proactive approach to offering support, with the underpinning themes of independence, health, choice and control, social inclusion, employment and raising awareness.

Linked to these documents, updated guidance to commissioners of health services calls attention to the need for practice-based commissioning and the important role of clinical engagement and internal partnerships in improving services and access. Other important policy developments comprise the review of mental capacity with the Mental Capacity Act 2005[52] and its code of practice; the Mental Health Act 2007[53] and various Acts and guidance related to discrimination, e.g. the Disability Discrimination Act 1995 and the Disability Discrimination Act 2005,[54] which imposes disability equality duties on public bodies.

A recent National Autistic Society campaign report[55] concluded that due to local political factors eligibility tends to be a chance event rather than a right. The report argues for a more outcomes-based approach, compatible with the personalisation agenda with a stronger focus on prevention and inclusion; fairness around access to services; and with a basic level of national minimum support. This is particularly relevant in the case of ASC, where minimal support at the right time, delivered in a highly individualised way, is claimed to be critical.[55]

Consultation on the White Paper, *Our health, our care, our say*, confirmed that people wanted access to support when they need it and then quickly, easily and with flexibility. People also wanted provision for a range of needs, with a greater focus on using preventative approaches to promote their independence and wellbeing.[51]

In summary, the current policy context, in particular the personalisation agenda, is highly

relevant to the development of improved social care for adults with ASC and should also provide a useful means for evaluating services. For some individuals with ASC and intellectual disability evidence suggests that services are becoming more appropriate and improving.[56] However, for those with more complex needs or those without intellectual disability, the picture is less positive. By focusing on the experience of the individual with ASC we should be able to determine how well services are performing against a set of outcome measures including quality of life.

## What does research show?

The strength of the research evidence in this area and in particular concerning the effectiveness of models of support and services is weak.[57]

There is a bewildering array of treatments and other interventions available claiming some form of effectiveness, from the modest to the extreme. These treatments frequently relate to the belief system of the therapist or organisation involved rather than an individual's need.[58] Treatments vary widely in nature and include special diets, supplements, a medical procedure such as chelation therapy (seeking to remove heavy metal from someone's body), medications, exercise regimes, behavioural programmes and a host of alternative and complementary approaches such as swimming with dolphins. Although there may be individual cases where one or more of these interventions may have appeared to have been helpful, with very few exceptions, such claims do not stand up to scientific scrutiny. Claims rely mainly on support from self-publicity, one-off case studies or stories, testimonials or invalid tests. That is not to dismiss them out of hand. Stories and case studies are important to our understanding but it is also important to recognise that they do not constitute strong evidence.

Ideally, opinion on any approaches to supporting people with ASC, including social care interventions, would be on the basis of systematic

and rigorous peer reviewed research with aggregated not 'cherry picked' results. In reality, there is a shortage of robust research about interventions[33] but limited evidence suggests that specialised individualised approaches achieve better outcomes than generic ones. The NAO research[9] indicated that adults supported by specialist teams were able to live in more independent and cost-effective housing. Significantly fewer of them were living in residential care compared with the numbers of people with ASC not supported by specialist teams. If replicated, these findings could be important in informing the way local services are organised, ensuring better relevance and cost effectiveness. More evidence is needed about how specially trained multi-disciplinary or multi-agency approaches work but they currently suggest a promising way forward.

Supported employment services have also been found to be associated with greater independence, reduced use of mental health services and higher income, although interestingly not increased friendships.[59] Indeed, new models of service for adults with ASC are evolving at an unprecedented rate in response to changes in public policy and new ideas and as a consequence of the higher profile and active self-advocacy of this group.

## Evidence about the use of social care for autistic spectrum conditions

The report from the NAO[9] on the use of social care confirms the problems of eligibility and access to appropriate social care but there has been relatively little systematic study in this area. The NAO report also highlights a discrepancy between the type of social care people say they need and what is provided.[9] This concurs with views of campaigning organisations like the NAS that eligibility criteria are misapplied leading to inappropriate and often wasteful forms of help

and in some cases to withdrawal of services for individuals with ASC who do not have an intellectual disability.[55]

The NAS 2008 report,[10] *I exist: the message from adults with autism in England*, estimated nearly two-thirds (63 per cent) of adults with autism do not have enough support to meet their needs and that 92 per cent of parents are worried about their son's or daughter's future when they are no longer able to care for them. Sixty-one per cent of adults with autism rely on their family financially and 40 per cent live with their parents. Sixty per cent of parents questioned for the National Autistic Society campaign believed that a lack of support had led to greater needs. At least 1 in 3 adults with autism were reportedly experiencing mental health difficulties due to a lack of support. Sixty-seven per cent of local authorities do not keep a record of how many adults with autism live in their area and 65 per cent do not even know how many adults with autism they actually support. A survey of carers found 76 per cent without support and 68 per cent without a carers' assessment.

The provision of social skills groups and support with leisure is rated as important by individuals with ASC and their families but is rarely available. Respite care and advocacy are also seen as important but it is the more traditional services involving day or residential care that are usually offered and for the more able there may be very little support available at all.[60,61]

Whilst reports such as *I exist*[10] are interesting, they are essentially campaign documents and the methodology, which involves biased sampling, reflects this. Caution is therefore needed in drawing conclusions from these documents. Nevertheless, such documents do not stand alone in terms of the messages they convey. The 2008 report from the Commission for Social Care Inspection, *Cutting the cake fairly*,[62] highlighted problems of fairness and a lack of transparency and observed that services continued to be service-led rather than needs-led. Additionally,

there was a high degree of fragmentation, 'silo thinking' and regional variation coupled with a failure to embrace the underlying principles of personalisation and social inclusion. This was seen as a consequence of competing organisational demands, in particular the issue of standardisation or conformity versus choice and flexibility. Although the report's findings were not restricted to people with ASC, it is still significant to highlight that almost two-thirds of people assessed for services felt they were not adequately advised on what was available.[62]

Work by Knapp and colleagues[32] showed that the numbers of adults with autism and an intellectual disability in residential care, supported living and in hospital, exceed those on the spectrum with no intellectual disability. Almost twice as many of those with ASC and no intellectual disability are said to live in private households compared with those on the spectrum with an intellectual disability. The costs of supporting most individuals with autism and an intellectual disability were predictably higher across most areas of social care, including employment support. Interestingly, the costs associated with lost employment for carers were higher for relatives of the more able population.

Access to housing and employment influences the need for social care and contributes towards personal stability and resilience. Various estimates show the level of employment of those with ASC without an intellectual disability to be around 12 per cent. Even then, these jobs do not reflect academic qualification and are seldom full-time.[59] Employment difficulties related to having responsibility for a person with ASC were present in the carer group in Howlin's study,[59] with almost half unemployed and only 22 per cent working full time. Fewer than five per cent of adults with ASC live completely independently and less than a third of adults were assessed as living with a reasonable level of independence. Some adults with autism have also found it difficult to settle in mainstream housing or

residential care designed for other groups and may have their residency terminated. The Valuing People ambition of 'choice of where and how you live' is seen as particularly restricted in this group.[63] Despite this, Harker observed that housing was not seen as a priority by service planners in transition planning.

Transport is also a critical factor in the take-up of social care and can be a barrier to social inclusion, with a wide range of difficulties reported in more than half of the population with ASC or their carers. Aspects of transport seen as problematic range from ease of using public transport to eligibility for disabled parking badges.

For black and minority ethnic communities or where English is not a first language, difficulties can be compounded and such people may face double discrimination.[64,65] This is an important area but at present there is a dearth of research on the subject.

Emerging evidence suggests that the use of personalised approaches in social care, including personal budgets and self-directed care, are producing higher levels of satisfaction among people with learning disabilities. Evidence also points towards the importance of simplifying the process and being clear about goals.[57] There is no evidence to suggest that a personalised approach would be problematic for people with ASC, as long as individual needs are properly assessed and catered for and people receive all necessary help in managing their budgets.

## What is it about the nature of autistic spectrum conditions that can prevent access?

Academic literature, government policy and guidance, and anecdotal evidence all support the view that adults with autism are excluded, or at risk of exclusion, from a wide range of services or opportunities and may face greater discrimination because of how they are perceived.[66] This includes exclusion from the wider disability movement and the academic community writing about disability.

Research confirms that when compared to their 'neurotypical' peers, individuals with ASC struggle in life skills and find the transition to adulthood particularly challenging, the majority remaining dependent on their parents. These challenges include forming and maintaining work relationships and personal relationships with the opposite sex and possessing insight into the nature of these difficulties.[13,67] Adults with ASC and intellectual disabilities may require intensive support to access services in the community. Their problems may be further exacerbated by behavioural and sensory challenges.[68] Less able people may be in danger from common hazards such as traffic and may need constant supervision to remain safe. On the surface, the barriers to public services appear less significant for individuals in such obvious need. The majority will be deemed eligible for help and catered for within learning disability services, although parents and carers may not always be satisfied that the quality of provision is 'autism friendly.'

Some individuals with ASC without an intellectual disability may have their problems misdiagnosed as mental illness rather than related to their cognitive profile.[16] Moreover, even if they do manage to obtain services there is a perception that services have to be fought for and may not be appropriate to their needs.[10] This is further complicated by those with secondary or co-morbid mental health difficulties, particularly depression, anxiety or adjustment reactions, requiring more intensive specialised opinion and access to informed psychiatric support where these disorders may be successfully treated.[18]

A further challenge to services concerns those individuals who by reason of their behaviour are in need of support but may not recognise or accept it or may choose not to access help at all. Some will be in conflict with their families, employers or members of the community. Others

may have low mood and depression, in some cases arising out of being bullied or personal stress and anxiety. They may be suspicious of and avoid contact with services, even though their families will often consider them to be in urgent need. Some may be referred eventually to mental health services. A small number may, as a result of deficits in theory of mind (i.e. lacking the ability to take others' perspectives) or social isolation commit offences against other persons and come to the attention of the police.[69] Greater access to support and counselling could be helpful but at present the evidence in support of such interventions is largely anecdotal.

## What is it about the way services are organised (e.g. eligibility criteria) that prevents access?

Entitlements that were available to children may disappear in adulthood and the process of qualifying for support from the statutory sector may need to begin again against a different set of criteria. The NAS was highly critical of the assumptions contained within the Fair Access to Care Services guidance as underestimating the level of risk and support needs of more able adults with ASC. The Society's campaign found that the Fair Access to Care Services criteria formed a barrier to access to services, with over 60 per cent of adults with Asperger's syndrome or high functioning autism reporting problems in trying to receive support from their local authorities and/or health services.

The Department of Health's *Better services for people with an autistic spectrum disorder* (2006)[41] set out how the Fair Access to Care Services guidance should be applied but the NAS report found that the guidance was rarely implemented.[55]

In the case of housing for adults with ASC without an intellectual disability, high numbers do not meet eligibility criteria as they fall outside the usual definitions of 'need'. Consequently, most will remain living with families or be left to the vagaries of the housing market; their difficulties compounded by their social problems and restricted income.[63]

Individuals with ASC, with or without intellectual disabilities, face difficulties over eligibility for other forms of social care, benefits and health care. Benefits may be difficult to access due to lack of clarity over eligibility, literal interpretation of rules on aspects of capacity by benefits staff, difficulties over completing official forms and factors relating to mobility; less than 20 per cent of people with ASC felt they were claiming what was due to them.[60]

Process is also important, especially the role of transition planning at school-leaving age, but also during other transitions through adulthood. There is consensus about how this can be improved through multi-disciplinary specialist teams starting early and with long-term follow-up. The dissatisfaction of families with many of the current agencies involved in transition is widely reported in sources including NAO[9] and NAS[10] reports.

A further aspect of the problem concerns access to information about services. Information can be hard to find. Local areas vary widely in terms of the information they provide. National information centres may provide some advice although information resources such as guidelines for eligibility criteria provided by the then Healthcare Commission, Commission for Social Care Inspection and Mental Health Act Commission were rarely used by service commissioners.

There is no evidence that the Disability Discrimination Act 1995 has so far improved access to employment, services, facilities or buildings. Anecdotal reports suggest that adults with ASC, especially those with additional

sensory needs, may be deterred from seeking employment, support or other forms of help because they are overwhelmed by the sensory and social challenges involved.

# What is it about the broad understanding of ASC that prevents access?

For an individual to access support they must first be deemed in need and eligible. The understanding of the nature of ASC by the service agency is therefore critical. While identification of those with more severe forms of the condition is easier, there is currently no good mechanism for identifying those with mild intellectual disabilities or those without intellectual disabilities.[70] Although it ought to improve the situation, there is some concern that the proposed review of diagnostic categories in 2012 may compound confusion and misunderstanding about different types of ASC.

The NAO found that the level of awareness among primary health care staff was very low with 80 per cent of GPs feeling they needed help in identifying individuals with ASC. Other studies have shown a similar low level of recognition of autistic conditions by health professionals generally[9,71] and within other relevant sectors such as employment[72] or criminal justice.[16,73] This is compounded by a shortage of expertise in the diagnosis of adults.

## The variety of autistic spectrum conditions

Adults with ASC are a highly heterogeneous group. In those without intellectual disability, it can be difficult to detect the condition, especially where there is little awareness or training. Presentation may be misleading, for example, good ability with language may mask severe difficulties in comprehension, problems with eye gaze may be perceived as hostility or evasiveness,

or a need for clarity or precision seen as contrariness.[69] Recognition is difficult enough for those diagnosed in childhood but more so for undiagnosed adults. Securing assessment and diagnosis in adulthood for previously undiagnosed individuals, especially those with more complex forms of the condition, may be particularly problematic but is vital in accessing services and support.[7]

The response of agencies to individuals who do not conform to socially accepted norms of behaviour is also relevant. The failure of some individuals with ASC to respond to social cues and culturally accepted norms of 'common courtesy' may cause them to present themselves in ways that are seen as offensive, socially inappropriate or odd. As a result they may be prohibited from accessing buildings and facilities. Some may have additional problems around appearance, hygiene and grooming.[74]

# What works?

Some evidence suggests that better outcomes and cost savings could be achieved by strategic planning and joined-up working, informed by a greater awareness and knowledge base. Some commentators argue that a shift in resources could be achieved through changes to delivery systems, for example through pooled budgets and joint commissioning.[9]

A growing literature describes successful services for adults with ASC but few of these services have been subject to systematic evaluation. Emerging evidence suggests that a specialist multi-disciplinary approach is associated with better outcomes through facilitating support in tandem with diagnostic services[9] but many of these innovative services are new and it is too soon to draw conclusions. The key variables may relate not to teams but to the skills of individuals within those teams. Analysis is also problematic due in part to poor recognition of autistic spectrum conditions.

There has been relatively few evaluations of different forms of interventions for people with ASC but some approaches have been shown to be beneficial. In summary, these include structured approaches linked to autism features, a need for predictability and reduction of personal anxiety.[72, 75–77] The application of personalised approaches fits well with such findings but advocates for personalisation would be wise to heed the potential problems associated with any blanket application of policy. Advocates of the policy of 'normalisation', subsequently called 'Social Role Valorisation',[78] in services were driven by a conviction that what they were doing was right. The policy was initially responsible for dramatic improvement in services. Over time however, the approach became increasingly dogmatic, narrow and prescriptive and the shortcomings were ignored or denied, eventually losing credibility and relevance.[79] The undoubted potential benefits of personalised approaches should not be blind to potential problems and scrupulous evaluation should be built in from the start.

Individuals with ASC are a diverse and heterogeneous group. They have unique needs, hopes, aspirations and individual preferences and they will make individual choices. They may have additional sensory or health needs and may have problems related to anxiety or other psychiatric conditions. A positive mindset and range of sophisticated approaches applied by appropriately trained and supported staff will be required to meet the various needs of people with ASC. Research should address a wide range of outcomes relating to choice, independence and quality of life but should also take account of other factors, including take-up of other services, effects on family life, risk levels and abuse. Research should also be concerned with analysing problems and shortcomings associated with different approaches.

We also need to know much more about how ASC affects different groups within the community for whom existing services may not currently acknowledge their existence or meet their needs. Among these are women, where the condition may not be recognised as readily as in men; black and minority ethnic groups, those in the offender or homeless population and those who are ageing. It is also important to know more about the wishes, demographics, needs and vulnerabilities of family members who may be supporting adults with ASC to ensure they are not subjected to a higher risk of social exclusion or harm.

For those with a learning disability, a more personalised approach has been shown to hold positive benefits for life experiences without incurring additional costs.[57] Individual research-based accounts of individuals with autism and an intellectual disability describe how such individuals benefited from person-centred approaches[80] and it would be reasonable to assume the same potential benefit for the more able group. Evaluation of supported employment programmes has shown the value of structured approaches, for example, individual coaching where the coach or mentor has knowledge of autism and a positive relationship with the person with ASC.[13,81] Indeed, it is difficult to see a convincing alternative given the widely differing level of need.

## Conclusion

In summary, 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. A prescriptive 'one size fits all 'approach to services, support and facilities will not be effective. A prudent investment in research, which has practical relevance and which leads to improved understanding of the effects of services would substantially improve the evidence base.

# Useful links

**Association for Real Change**
An umbrella organisation for services for adults with learning disabilities and autism.
**www.arcuk.org.uk/**

**Asperger's Syndrome Foundation**
A London-based charity which aims to promote high-quality support and services, and to enable people with Asperger's syndrome to develop into members of the community who are respected for their contribution and recognised for their unique differences.
**www.aspergerfoundation.org.uk/**

**Autism Centre at Sheffield Hallam University**
Centre dedicated to social care autism related research.
**www.shu.ac.uk/theautismcentre/**

**Autism Europe**
An international association whose main objective is to advance the rights of people with autism and their families and to help them improve their quality of life.
**www.autismeurope.org/**

**Autism**
An international peer reviewed journal for research and practice (published by SAGE).
**http://aut.sagepub.com/**

**Autistics.org**
The purpose of the autistics.org project is to connect autistic people with the services we need to live whole and happy lives. Its immediate goal is to build a global database of information and resources by and for persons on the autistic spectrum.
**www.autistics.org/**

**British Association for Supported Employment**
Membership organisation for supported employment agencies and supported businesses in the UK.
**www.afse.org.uk/**

**The Challenging Behaviour Foundation**
UK charity which exists to demonstrate that individuals with severe learning disabilities who are described as having challenging behaviour can enjoy normal life opportunities when their behaviour is properly understood and appropriately managed.
**www.thecbf.org.uk/**

**Department of Health – Autism**
Department of Health site on autistic spectrum conditions which includes progress updates on the adult autism strategy
**www.dh.gov.uk/en/SocialCare/Deliveringadult socialcare/DH_079431**

**Journal of Autism and Developmental Disorders**
International journal which covers severe psychopathologies found in childhood, including autism and childhood schizophrenia.
**www.ingentaconnect.com/content/klu/jadd**

**Journal of Applied Research in Intellectual Disabilities**
Published on behalf of the British Institute of Learning Disabilities, this journal covers many aspects of learning disabilities including autism.
**www.blackwell-synergy.com/loi/jar**

**The National Autistic Society**
Charity that champions the rights and interests of all people with autism and aims to provide individuals with autism and their families with help, support and services that they can access, trust and rely upon and which can make a positive difference to their lives.
**www.nas.org.uk/**

**Research Autism**
UK charity exclusively dedicated to research into interventions in autism.
**www.researchautism.net/pages/welcome/home.ikml**

**Social Exclusion Task Force**
A UK government agency which aims to coordinate the Government's drive against social exclusion, ensuring that the cross-departmental approach delivers for those most in need.
**www.cabinetoffice.gov.uk/social_exclusion_task_force.aspx**

**University Students with Autism and Asperger's Syndrome**
UK site run by a university student who has Asperger's syndrome and is for other students with autistic spectrum disorders.
**www.users.dircon.co.uk/~cns/index.html**

# Related SCIE publications

At a glance 21: Personalisation briefing: Implications for people with autistic spectrum conditions and their family carers (2010)

SCIE Guide 33: Facts about FACS 2010: A guide to Fair Access to Care Services (2010)

e-Learning resource: Fair Access to Care Services (FACS) 2010 training module

SCIE's work on adults' services
**www.scie.org.uk/adults/publications.asp**

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# About the development of this product

## Scoping and searching

Scoping was carried out in August 2009, with further searching in September 2009.

## Peer review and testing

The author is a topic expert. Production, product and key messages were internally/externally peer reviewed by Project Advisory Group (including people who use services and carers).

## Future work

A practice enquiry was subsequently commissioned (as evidence is sparse): a guide will be produced in 2011 based on these products.

## About SCIE research briefings

SCIE research briefings provide a concise summary of recent research into a particular topic and signpost routes to further information. They are designed to provide research evidence in an accessible format to a varied audience, including health and social care practitioners, students, managers and policy-makers. They have been undertaken using methodology developed by SCIE. The information on which the briefings are based is drawn from relevant electronic databases, journals and texts, and where appropriate, from alternative sources, such as inspection reports and annual reviews as identified by the authors. The briefings do not provide a definitive statement of all evidence on a particular issue. A full account of the method used in identifying and organising material for this publication is available at **www.scie.org.uk/publications/briefings/files/researchbriefingguidance2009.pdf**

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# SCIE research briefings

1 Preventing falls in care homes

2 Access to primary care services for people with learning disabilities

3 Communicating with people with dementia

4 The transition of young people with physical disabilities or chronic illnesses from children's to adults' services

5 Respite care for children with learning disabilities

6 Parenting capacity and substance misuse

7 Assessing and diagnosing attention deficit hyperactivity disorder (ADHD)

8 Treating attention deficit hyperactivity disorder (ADHD)

9 Preventing teenage pregnancy in looked-after children

10 Terminal care in care homes

11 The health and well-being of young carers

12 Involving older people and their carers in after-hospital care decisions

13 Helping parents with a physical or sensory impairment in their role as parents

14 Helping parents with learning disabilities in their role as parents

15 Helping older people to take prescribed medication in their own homes

16 Deliberate self-harm (DSH) among children and adolescents: who is at risk and how it is recognised

17 Therapies and approaches for helping children and adolescents who deliberately self-harm (DSH)

18 Fathering a child with disabilities: issues and guidance

19 The impact of environmental housing conditions on the health and well-being of children

20 The implementation of individual budget schemes in adult social care

21 Identification of deafblind dual sensory impairment in older people

22 Obstacles to using and providing rural social care

23 Stress and resilience factors in parents with mental health problems and their children

24 Experiences of children and young people caring for a parent with a mental health problem

25 Children's and young people's experiences of domestic violence involving adults in a parenting role

26 Mental health and social work

27 Factors that assist early identification of children in need in integrated or inter-agency settings

28 Assistive technology and older people

29 Black and minority ethnic parents with mental health problems and their children

30 The relationship between dual diagnosis: substance misuse and dealing with mental health issues

31 Co-production: an emerging evidence base for adult social care transformation

32 Access to social care and support for adults with autistic spectrum conditions (ASC)