

Evidence Cluster: Effectiveness of support for adults with Autistic Spectrum Disorder

Issue Many adults with Autistic Spectrum Disorder (ASD) experience problems accessing appropriate, ASD-specific services and support, with 63% reporting that they do not get enough support to meet their needs (NAS 2008). It is widely recognised that these individuals can often fall down the gap between learning disability and mental health services. A lack of understanding of ASD may prevent appropriate and effective services being provided (DH 2006; NAS 2008).

In the current policy context where the need for appropriate ASD-specific services is now recognised, it is important to develop an awareness of the existing evidence for approaches to enabling adults with an ASD to live as independently as possible.

Content of this evidence cluster This evidence cluster summarises the existing evidence for the effectiveness of a number of approaches to supporting adults with ASD in living independently. It focuses on formal support services such as day services, residential care, supported employment and respite care. Pharmacological and therapeutic interventions such as music therapy, speech therapy and cognitive behavioural therapy are not discussed.

Definition of key terms This evidence cluster refers mainly to Autistic Spectrum Disorder (ASD), autism, and Asperger syndrome. **Autistic Spectrum Disorder (ASD)** usually refers to autism and Asperger syndrome in combination, but it can also refer to a range of other diagnoses including high-functioning autism (HFA), pervasive developmental disorder – not otherwise specified (PDD-NOS), classic autism or Kanner autism, semantic pragmatic disorder, and atypical autism, some terms being interchangeable. The phrase **spectrum disorder** is used because ASD affects people in different ways and to varying degrees (NAS website 2008).

People who have been diagnosed with an ASD will share similar difficulties and support needs. They experience three main areas of difficulty, sometimes referred to as the **triad of impairments**:

- social interaction (for example, appearing indifferent to other people, or having difficulty expressing their own feelings)
- social communication (for example, not understanding the meaning of facial expressions or tone of voice)
- social imagination (for example, having difficulty planning for the future).

(DH 2006a; NAS 2008)

The National Autistic Society (NAS) describes **autism** as ‘a lifelong disability that affects how a person makes sense of the world, processes information and relates to other people’ (NAS website 2008). People with autism can have accompanying learning disabilities or mental health needs. Individuals with **Asperger syndrome** similarly experience difficulties with social, occupational and other areas of their life, but have fewer problems with speaking and are often of average, or above average, intelligence. It is less common for adults with Asperger syndrome to have accompanying learning disabilities (NAS website 2008; DH 2006a).

Policy background Until recently, there has been little policy in England that has been specifically related to services for adults with an ASD. Moves towards remedying this have occurred over the past three years.

In November 2006, the government published *Better services for people with an autistic spectrum disorder: A note clarifying current Government policy and describing good practice*. It focused on people aged 16 years and over with autism, high-functioning autism and Asperger syndrome, and its purpose was to encourage the development of local agendas for action in health and social care. Simply clarifying existing government policy and describing good practice, it did not include any new policy, but explained what existing policies meant for local providers in terms of services for adults with an ASD. It summarised the relevance of a number of key government policies and publications in relation to adults with ASD, including *Our Health, Our Care, Our Say* (DH 2006b), *Fair access to care services - guidance on eligibility criteria for adult social care* (DH 2003), and the *National service framework for mental health* (DH 1999). An important message from this document was that the situation at the time, whereby some people with an ASD were 'falling through' local services (in particular between mental health and learning disability services) was unacceptable and contrary to the intention of government policy (DH 2006a).

The National Autistic Society published an important report in early 2008 as part of its 'Think Differently About Autism' Campaign (NAS 2008), arguing that current government policy does not meet the needs of adults with ASD. The report explores the experience of adults with ASD and their families in England and puts forward recommendations for changes that will help to improve their lives. It highlights the problem that the number of people with ASD in England is currently unknown, making it difficult to plan services appropriately. It also emphasises the range of barriers that are preventing adults from accessing support, and notes that where services *are* available, they are often inappropriate for meeting the needs of adults with an ASD.

In May 2008 the Department of Health announced the development of its Adult Autism Strategy, which will be the government's first strategy on adults with autism and Asperger syndrome. Due to be published in 2009, the strategy will focus on areas such as mental health, social care, housing and further education. To inform the strategy, a prevalence study will be undertaken in the first instance, looking at numbers of adults with autism and the transitions needs of young people.

The evidence – setting the scene

Nine original studies are included in this evidence cluster, all of which explore some aspect of the impact of services upon the quality of life of adults with ASD and their carers. Some studies explore the impact of receiving services more generally, while others explore a specific type of, or approach to, support, such as supported employment or residential care. The approaches to support are diverse, but in combination the studies are able to give a clear initial indication of what types of services are likely to help improve the lives of adults with an ASD and their carers.

It is important to note that these studies have adopted a range of criteria for their participants. As a result, there are some differences between the groups, so caution should be applied when comparing the findings of the studies. For example, some studies include only adults with Asperger syndrome while others specifically exclude this group. Similarly, in some studies all participants have accompanying learning disabilities and in others they do not.

The evidence on what works for adults with Autistic Spectrum Disorder – key messages

Formal support services have the potential to improve the lives of adults with an Autistic Spectrum Disorder

There is evidence to suggest that formal support services in general can help improve the quality of life of adults with an ASD, with benefits including an increase in service users' social participation. The beneficial role of support may be enhanced when services are ASD-specific,

rather than being provided within existing learning disability or mental health services. Where services are flawed or there is unmet need, this can have a negative impact on individuals.

In a US study of 235 adults and adolescents with autism (excluding individuals with Asperger syndrome and PDD-NOS) living at home, formal support services improved the lives of the participants (Orsmond and colleagues 2004). The researchers demonstrated that the greater the number of services received by service users, the greater the participation in social and recreational activities. A possible reason given for this is that 'there may be spillover effects of the provision of community-based services for adolescents and adults with autism that enlarge their social worlds'.

In further support of this are the findings of Renty and Roeyers (2006), who explored the factors influencing quality of life in 58 adults with autism, Asperger syndrome or PDD-NOS, all of who had an IQ of 70 or more. They found that support characteristics accounted for 51% of the variation in quality of life between study participants ($p < 0.001$), while age, gender, education, living arrangements, intimate relationships, disability characteristics, IQ and autism-specific traits all had no significant impact. However, unlike Orsmond and colleagues' findings, it was not the level of *received* formal support that was important. Instead it was the extent to which there were *unmet* support needs that was crucial: 'the discrepancy between needed and received formal support was strongly associated with quality of life'. Informal support was also important; this is discussed below. In a later study by the same authors, this time focusing on the impact of formal support on individual and marital adaptation, there was further support for the idea that the level of services received is not important (Renty and Roeyers 2007).

In a study of 26 carers of adults with ASD, 14 participants named social services as a service that had been particularly helpful (Hare et al 2004). These carers reported that they appreciated the staff and management of day services, and practical help from social workers with activities such as filling in forms. Seven participants, however, named social services as a service that had been particularly unhelpful: services had been unreliable, causing confusion and distress both for the carer and for the adult with ASD. They reported that carers did not turn up when they were supposed to (a particular problem as people with ASD place importance on routine and predictability), and that there was a general lack of communication and a decline in the services available. Furthermore, concern was expressed about the high staff turnover at residential homes.

In the same study, there were particularly positive findings in relation to day services. These were found to be appropriate for the majority of adults who used them (14 of 20 participants), particularly a local autism-specific day service. Where services were felt to be inappropriate, this was for reasons such as them being too small, being understimulating, providing a lack of opportunity to learn new skills, and staff not being knowledgeable about autism. A majority of respondents reported that the service user 'enjoys college/day service' (69% said 'very true') and that the 'college/day service supports them as parents' (65% said 'very true'). In response to a series of negative statements, a majority of respondents reported that it was 'not at all true' that the 'college/day service staff do not understand [the] person' (69%), or that the 'college/day service [is] unable to cope with [the] person' (69%). These findings are encouraging but do require further exploration of what can be done to improve the experience of the one third of respondents who did not give positive responses.

It is important to ensure that service users' needs are assessed on an individual, person-centred basis, and that it is not simply the label of Autistic Spectrum Disorder that is taken into account when determining which services are provided. For example, one study showed that individuals who scored highly on an ASD screening questionnaire, but who did not have a formal diagnosis of ASD, were at a disadvantage. The authors found that the difference in quality of life between the two groups was greater than the difference in disability, indicating some potentially unmet need (Bennett et al 2005).

Supported employment is a key form of support to adults with an ASD

Supported employment schemes, incorporating tailored approaches to supporting adults with an ASD, can be an effective way of helping individuals to live more independently. Without such schemes, it may be difficult for these adults to gain and remain in employment, and where it is gained, it may not be appropriate to the skills of the individual – for example, in Hare and colleagues' study of 26 adults with ASD, only one adult had had any paid or voluntary vocational experience, as an office junior and cleaner (Hare et al 2004). Two studies, described below, evaluated distinct approaches to supporting adults with ASD in employment.

A scheme entitled 'Prospects' was evaluated over an eight year period, with positive outcomes (Howlin et al 2005). The scheme aimed to find work for individuals with autism or Asperger syndrome, and support them in their employment. Over the study period, 192 jobs were found, of which 70% were for more than 16 hours per week and were sustained for more than 13 weeks, and 58% were permanent contracts. The types of employment gained were as follows: administrative, technical or computer related (52.5%), office-based work (20.5%), catering, cleaning or factory work (10%), and retail (8%) – the high proportion of administrative, technical or computer related positions was felt to indicate that the employment found was well suited to the educational and intellectual capabilities of the individuals involved. Nineteen individuals who took part in an early pilot phase of the work were followed up after seven years, and thirteen had remained in permanent jobs.

Individuals tended to have a positive experience of the supported employment scheme. For example, of 89 clients who were assessed in detail between 2002 and 2003, 59 (66%) were in work, and of these, 50 were generally satisfied with their job, while 45 felt their job lived up to their expectations. All but one said their registration with Prospects had been helpful, while 44 said they could not have managed without the help of the scheme. Service users reported that, for example 'I feel much more confident than before and better able to cope with my present job', while employers made comments such as 'it has given me a greater insight into autism', and 'I've gained pleasure from seeing the employee grow in confidence'. A large majority of the 61 senior managers interviewed were either very satisfied (47) or satisfied (13) with the scheme (Howlin et al 2005).

In a very different scheme, working with four non-verbal adults who had been diagnosed with ASD as well as learning disabilities, Lattimore and colleagues (2006) found a specific approach to supported employment to be effective. The approach focused on job-site training plus simulation training to help the individuals carry out their roles successfully. Overall, the researchers found that adults with autism acquired work skills more quickly when job-site training was supplemented with simulation training. For example, the two workers who received simulation training for an envelope preparation task required a maximum of three 'probes', compared to the two workers who received job-site training only, who required at least six probes. The authors felt that the approach provided some solution to the problem that only a limited amount of time within supported work can be spent on training, relative to time spent on duties. It should be noted, however, that this was a very small study and the participants had more severe disabilities than those in some of the other studies discussed in this evidence cluster.

Innovative approaches to residential care, tailored to the specific needs of adults with Autistic Spectrum Disorder, can be effective

ASD-specific residential care was demonstrated to be effective in two studies which used contrasting approaches to helping adults with an ASD live as independently as possible. Where residential care is not tailored to the specific needs of adults with an ASD, difficulties may occur: for example in Hare and colleagues' study, concern was expressed by families regarding the high turnover of staff, due to residents' need for routine and predictability (Hare et al 2004).

A training programme in a residential home for people with autism in Greece, based on the TEACHH method (Treatment and Education of Autistic and related Communication Handicapped Children), was evaluated and found to be effective (Siaperas and Beadle-Brown

2006). Twelve adolescents and adults with an ASD, as well as learning disabilities ranging from mild to severe, took part in the study. The programme included structured teaching, with a focus on the individual needs of the person with autism, and a strategy that built on their existing skills and interests. Key aspects of the approach included:

- ensuring that all the areas were physically arranged so that the people with autism had continual visual cues in order to understand what was expected from them
- providing daily visual schedules based on each person's ability, 'a schedule of work and play...that each person with autism learns to look at...and follow its instructions in order to do the next activity independently'.

Using structured interviews with the trainers and observation of the residents, the researchers found that there was a significant improvement in residents' personal independence, social abilities, and functional communication, over a six-month period. Looking at more specific areas of change, they found that there was a significant improvement in the extent to which participants looked at people's faces when talking to them. The researchers also found that after six months within the residence, the participants spent more time engaged in activity and social behaviour, and there was a trend towards people being involved in more activity of different types. It should be noted that this was a small study: the authors acknowledged that ideally there would have been a matched control group in order to give stronger conclusions (Siaperas and Beadle-Brown 2006).

In a second study the impact of 'active support training' carried out within community housing for adults with learning disabilities was evaluated over a 21 month period (Smith et al 2002). Active support training is designed to change how staff support resident activities through planning and monitoring resident activity, and enable them to assist residents to undertake activities which they are not fully independent to do by themselves. It aims to ensure that the assistance provided is better matched to residents' support needs. This study included 188 participants with learning disabilities, of whom 52% were 'assessed as having the triad of social impairments characteristic of autistic spectrum disorder'. The authors explored the effectiveness of staff in supporting resident activity, and their impact in relation to residents' challenging behaviour, adaptive behaviour, psychiatric diagnosis and autism.

Active support was shown to be an effective intervention for people with ASD. There were significant increases in Yule's Q -values for engagement (defined as all occurrences of social, domestic, personal and other non-social engagement) where residents were given both verbal instruction AND non-verbal assistance, and also for engagement where they were given only non-verbal assistance. This was true among those residents with the triad of social impairments characteristic of ASD ($p < 0.05$ and $p < 0.01$ respectively) as well as those without.

Informal carers provide a key source of support for adults with autistic spectrum disorder - so respite services for carers are important

Informal carers of adults with ASD can face great challenges in their caring role, often with a low income and with very little external support (both formal and informal), particularly when compared to carers of children with ASD. Where there is unmet need for support for carers, this can have a negative impact, which could arguably be offset by the provision of more supported breaks from caring.

Evidence suggests that family members and other informal carers play a key role in improving the quality of life of adults with an ASD. This is demonstrated in one study which found that lower levels of perceived social support from family, friends and acquaintances were related with greater psychosocial distress (Renty and Roeyers 2007). Marital adaptation was significantly associated with more received and perceived social support from the spouse and from family, friends and acquaintances. The same authors found in an earlier study that, in relation to perceived informal support, participants felt they counted particularly on the support of their mother (78%), father (43%), siblings (69%), friends (76%), other family

members (15%), and their partner (9%). Perceived, as opposed to received, informal support correlated strongly with quality of life ($p < 0.001$) (Renty and Roeyers 2006).

Studies have shown that family carers face great challenges in their role, indicating that external support is crucial. In Hare and colleagues' study (2004), family carers reported that aggression was the most challenging behaviour shown by the person they cared for, with several reporting that they had been physically attacked. Family members were understanding of the causes of this aggression in the adult with ASD, and tended to report that it was related to feelings of frustration, including not being able to cope with everyday life, or not understanding social rules or why they could not do things they had observed others doing. The social and financial circumstances of the carer could sometimes enhance the difficulties they experienced: only three of the 26 participants were working full time, and the majority of families were on lower than average incomes, with 43% on less than £200 per week, many of whom were retired.

Supported breaks from caring were found to be an important way of helping carers in their role. Unfortunately, Hare and colleagues reported that only 12 of the 26 carers in their study were receiving short-term respite, and of these, the majority rated it as 'appropriate but insufficient'. Carers reported that 'breaks from caring' were their main area of unmet need (89%), and that this could simply mean a few hours in the evening; not necessarily overnight. A significant relationship was found between levels of unmet need and the participants' score in the C-GHQ-12 questionnaire, which was used to measure longstanding problems relating to psychological wellbeing - unmet need was the main factor associated with emotional distress. In the absence of sufficient respite care, the key source of support for carers tended to be family rather than formal support services. The most important informal support for the main carer came from their partner, with 58% rating this source as 'very helpful' (27%) or 'extremely helpful' (31%).

Specific strategies for providing services for adults with ASD may be beneficial

Currently, it is recognised that adults with an ASD can often fall through the gap between learning disability and mental health services, and that it is important for local authorities to develop ASD-specific services in order to resolve this problem.

In support of this, Hare and colleagues (2004) reported a strong theme raised by the majority of families, which was a need for autism-specific day care, together with more intervention in the day centres, such as speech therapy, to enable their son or daughter to develop and live more independently. They also expressed a need for more training in autism for staff and carers. 'There is a need for the development of autism-specific programmes for those...whose general abilities place them outside the remit of learning disability provision'.

In contrast, however, Bennett and colleagues argued that the needs of individuals with ASD were being met without the need for a specific autism strategy, and argued that at present, 'all services appear to be provided in line with individual need, rather than on the basis of a diagnosis alone' (Bennett et al 2005). Within this study, which took place in a Learning Disability Service within an NHS trust in northwest England, individuals with autism in fact received more services, which included day centres, care coordination, and input from health services psychology, and behavioural services, than 'low scorers' – those without ASD ($p < 0.05$). Any differences in quality of life between those with and without an ASD were explained by differing levels of disability or challenging behaviour, rather than the presence or absence of a diagnosis of autism. An important point though, was that where carers had a greater knowledge of autism, service users reported a better quality of life and took part in more activities. Although overall the authors argue that an autism-specific strategy is not needed, this finding suggests that measures to improve carer knowledge of ASD would be valuable, whether within existing learning disability strategies or within more specialised ASD strategies.

Conclusion While further research into the effectiveness of support services for adults with ASD will be valuable, alongside prevalence studies regarding the numbers of adults in England who have been diagnosed with the condition and levels of unmet need, a number of tentative conclusions can be drawn.

Formal support services can improve the quality of life of adults with an ASD, particularly where ASD-specific approaches are adopted rather than relying on existing learning disability and mental health services. However, communication and continuity are crucial, as services have the ability to cause frustration and confusion if not provided appropriately. Effort must be taken to identify areas of unmet need, both for service users with an ASD and their carers.

It may be possible to provide suitable support within existing learning disability and mental health service, but this is arguably not ideal for those adults with an ASD who have *not* been diagnosed with a learning disability or mental health problem. Where support is provided within existing services, it is still necessary to take measures to ensure that staff have a clear understanding of the specific needs of adults with an ASD and how to help them live independently.

It is particularly important that services are provided based on detailed assessment of individuals' needs, rather than the existence or otherwise of the label of ASD: 'given the significant association of quality of life with the number of unmet formal support needs, professional supporters should strive to meet all individual needs that persons with ASD report....there should be a greater emphasis on the assessment of met and unmet needs, from the individual's viewpoint' (Renty and Roeyers 2006).

In specific areas such as supported employment and residential care, ASD-specific strategies appear to be even more beneficial. By developing strategies that are tailored to the specific needs and difficulties experienced by adults with ASD, it is possible to have positive outcomes, with improved independence being of particular importance. Supported employment schemes in particular are valuable in both demonstrating confidence in the ability of adults with ASD to be independent, and in giving them greater confidence in themselves.

Informal carers are an important source of support for adults with ASD, and therefore a fundamental way of relieving pressure on providers of formal support. Formal support services can ensure that family members and informal carers are able to fulfil the caring role as effectively as possible by recognising their importance and providing support such as short breaks from caring.

References

Bennett H E, Wood C L and Hare D J (2005) Providing care for adults with autistic spectrum disorders in Learning Disability services: Needs-based or diagnosis driven? *Journal of Applied Research in Intellectual Disabilities*. Vol 18, pp57-64

[DH \(2006a\) *Better services for people with an autistic spectrum disorder: A note clarifying current Government policy and describing good practice*. London: The Stationery Office](#)

[DH \(2003\) *Fair access to care services - guidance on eligibility criteria for adult social care*. London: The Stationery Office](#)

[DH \(1999\) *National service framework for mental health: modern standards and service models*. London: The Stationery Office](#)

[DH \(2006b\) *Our Health, Our Care, Our Say: a new direction for community services*. London: The Stationery Office](#)

Hare D J, Pratt C, Burton M, Bromley J and Emerson E (2004) The health and social care needs of family carers supporting adults with autistic spectrum disorders. *Autism*. Vol 8, No 4, pp425-444

Howlin P, Alcock J and Burkin C (2005) An 8 year follow up of a specialist supported employment service for high-ability adults with autism or Asperger syndrome. *Autism*. Vol 9, No 5, pp533-549

Lattimore L P, Parsons M B and Reid D H (2006) Enhancing job-site training of supported workers with autism: A reemphasis on simulation. *Journal of Applied Behaviour Analysis*. Vol 39, No 1, pp91-102

Orsmond G I, Krauss M W and Seltzer M M (2004) Peer relationships and social and recreational activities among adolescents and adults with autism. *Journal of Autism and Developmental Disorders*. Vol 34, No 3, pp245-256

Renty J and Roeyers H (2007) Individual and marital adaptation in men with autism spectrum disorder and their spouses: The role of social support and coping strategies. *Journal of Autism and Developmental Disorders*. Vol 37, pp1247-1255

Renty J O and Roeyers H (2006) Quality of life in high-functioning adults with autism spectrum disorder: The predictive value of disability and support characteristics. *Autism*. Vol 10, No 5, pp511-524

Siaperas P and Beadle-Brown J (2006) A case study of the use of a structured teaching approach in adults with autism in a residential home in Greece. *Autism*. Vol 10, No 4, pp330-343

Smith C, Felce D, Jones E and Lowe K (2002) Responsiveness to staff support: Evaluating the impact of individual characteristics on the effectiveness of active support training using a conditional probability approach. *Journal of Intellectual Disability Research*. Vol 46, No 8, pp594-604

[The National Autistic Society \(2008\) *I Exist – The message from adults with autism in England*. London: The National Autistic Society](#)

The National Autistic Society website: <http://www.autism.org.uk> (accessed 31st August 2008)