

People with autistic spectrum disorders (ASD) are not receiving the advocacy support that they need. This is due to a lack of funding by local and central government and the unmet training requirements of advocacy organisations. As a consequence, advocacy organisations are unable to provide adequately for this group

Advocacy

Advocacy is taking action to help people say what they want, secure their rights, represent their interests and obtain services they need.¹

Well over 1,000 independent advocacy organisations throughout the UK provide various forms of advocacy using both paid staff and volunteers. Some work with people with mental health problems, others with people with learning difficulties, while some schemes are generic. All should offer support that is clearly independent from service providers, carers or public authorities.

Advocacy and autism

Autism is a lifelong developmental disability that affects the way a person communicates and relates to people around them. The National Autistic Society estimates that 1 in 110 people have an ASD (including Asperger syndrome), almost 1% of the population (~520,000 people in the UK). Carers often play an important part in supporting people with ASD, but continuing reliance on their families may inhibit their independence. This is why access to advocacy can be important in helping adults with ASD to have a greater degree of independence.

All people with ASD have impairments in social interaction, social communication and imagination. They therefore need help to express their aspirations, interpret and process information regarding their rights and to request relevant services.

People with Asperger syndrome, because of their fluent language, and average or above average IQ level, may not appear to need access to advocacy services. This can be misleading and it is important that advocacy services are available for all people with ASD.

"I was told I don't need an advocate as I'm too able."

Demand for advocacy

Adults with ASD involved in The National Autistic Society (NAS) report *Autism: Rights in Reality* (2003)² wanted to access independent advocacy,

but very few had been able to do so. Of those who had, the feedback was very positive.

"Yes I'm very happy with my advocate, I only wish I knew her all those years ago."

Advocacy support is needed with:

- Transition to adulthood and adult services
- Access to housing
- Access to employment
- Assistance with social integration and life planning
- Access to health services.

In *Autism: Rights in Reality* only 11% of carers stated that the adult they cared for had ever used an independent advocate. It is clear that despite *Valuing People*³ adults with ASD are still missing out on advocacy support. This may be because *Valuing People* funding has focused on greater geographical spread for advocacy, not on providing for those with complex communication needs.

Good Practice

Speakeasy (Autism Spectrum Disorder Advocacy Service – Hampshire)

Speakeasy offers an advocacy service to people of all ages and all abilities with an autistic spectrum disorder. People are put in contact with Speakeasy through the Hampshire Autistic Society, Social Services or they can contact Speakeasy themselves directly.

All the advocates are volunteers who receive training from Speakeasy both in relation to advocacy itself and in the way advocacy can relate to people with an autistic spectrum disorder.

As well as a one to one service, Speakeasy also encourages self-advocacy in small groups of 3 or 4. The service is free to people with an autistic spectrum disorder.

"Before I found out about Speakeasy I struggled to ask for help but now I can ask for the services I need."

Advocacy in Scotland (a model for England and Wales?)

Advocacy Safeguards Agency

The Advocacy Safeguards Agency (ASA) is funded by the Scottish Executive Health Department to further the Executive's commitment to independent advocacy.

The ASA has four main tasks:

- To work with NHS Boards and local authority commissioners to facilitate the development of independent advocacy across Scotland
- To evaluate independent advocacy organisations
- To develop policy and good practice in relation to independent advocacy
- To research independent advocacy.

Scottish Independent Advocacy Alliance (SIAA)

The SIAA was set up in April 2002 to ensure the provision of Advocacy is available to any vulnerable person who needs it in Scotland. It will be funded for three years by the Scottish Executive.

¹ Definition from the Independent Advocacy Campaign (2002).

² Broach S. et al (2003) *Autism: Rights in Reality*. London: National Autistic Society

³ Department of Health, (2001) *Valuing People: a new strategy for learning disability for the 21st century*. London: Department of Health.

Conclusion

What advocacy services need

The National Autistic Society contacted 55 generic, learning disability and mental health advocacy schemes, a representative sample from across the UK.

Most advocacy organisations (68%) do support people with ASD. There is an obvious discrepancy here: **68% of advocacy organisations offer support to people with an ASD but only 11% of people we surveyed accessed this support.**

This could mean that advocacy organisations are not prioritising people with ASD. It also raises questions about the remit, scope and resource capacity of independent advocacy organisations to provide support for approximately 330,000 adults with an ASD in the UK.

When we asked independent advocacy organisations what they find challenging about advocating for people with ASD the answers confirmed the diversity of problems

experienced by individuals with ASD when trying to communicate their needs:

- Lack of understanding of autistic spectrum disorders
- Communication difficulties
- Difficulties people with ASD have with choice
- Difficulties in finding out what the individual wants
- Problems in building relationships with the individual
- Gaining informed consent
- Ethics of advocating for people with communication difficulties.

Advocacy organisations have an obvious need for training in awareness and understanding of autism. Over half the organisations had not previously been in contact with the NAS despite the fact that many advocated for people with an ASD. More than three quarters had not been in contact with a local autistic society. The majority of independent advocacy services are therefore operating in isolation with regards to autism.

Policy Context

Recent Government documents have highlighted the importance of advocacy services. *Valuing People* states that its long-term aim is 'to have a range of independent advocacy services available in each area so that people with learning disabilities can choose the one which best meets their needs.' *Valuing People* created two advocacy funding streams, one for citizen advocacy and one for self-advocacy.

Other reports which included information about advocacy services were: *Making it Work*. Social Services Inspectorate (Sept 2001), *Building Capacity and Partnership in Care – An agreement between the statutory and independent social care, health care and housing sectors*. Department of Health (Oct 2001), *Domiciliary Care Standards Consultation*. Department of Health (Oct 2001) and *National Minimum Standards for Care Homes for Younger Adults*. National Care Standards Commission (Dec 2001).

The Mental Health (Care and Treatment) Scotland Act (2003) gives people with a 'mental disorder' the right to access independent advocacy and places a duty on health and local authorities to secure its availability.

However, Sections 1 and 2 of the *Disabled Persons Act (1986)*, which would have given people with a disability the right to advocacy, have never been implemented.

The National Autistic Society has a three-year initiative to develop training and information for independent advocacy organisations. It is also a member of the Independent Advocacy Campaign (IAC), calling for better advocacy provision for people physical, communication and sensory impairments. The NAS has secured funding to pilot two user groups to equip people with ASD to have their voice heard within the organisation and the wider community.

Independent advocacy services are a perfect example of cost-effective, low-level support that facilitates independent living. Those adults with experience of independent advocacy testified to its value, but more advocacy organisations need to be equipped with the skills to work effectively with this group. Access to independent advocacy should be seen as a basic human right rather than as simply good practice or an optional addition to services.

People with ASD are falling through the gaps between mental health and learning disability advocacy providers. More funding is needed from central government to help advocacy organisations widen their scope, train their staff and volunteers, and increase the number of people with ASD gaining access to their services.

The Government has continually made reference to the importance of advocacy in promoting independence. Financial support and training will be vital to enable independent advocacy organisations to deliver this vision for people with ASD.

Recommendations

- Advocacy organisations, local authorities and local autistic societies to foster tri-partite links to promote local advocacy initiatives for people with ASD
- Government departments to examine possibility of similarly funded project to that of ASA in Scotland
- Government departments and local authorities to target funding to independent advocacy services to include people with ASD within their client group
- NAS to support advocacy organisations to train their staff in autism
- Independent advocacy organisations to develop policies and guidelines to support advocates working with people with ASD



The National
Autistic Society

Registered as a charity no 269425
© The National Autistic Society, 2003

Angie Lee-Foster, Head of
Advice and Advocacy:
020 7903 3763
aleefoster@nas.org.uk

Autism Helpline, supported by
Barclays: 0870 600 85 85

NAS Policy and Campaigns:
020 7903 3558
policy@nas.org.uk

Over half the calls to the Autism Helpline could benefit from advocacy support.