

Support Organisations

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Abstract

Too many people with autism struggle to access the support and services they need. Recent research indicates that 62% of adults with the condition believe that they do not have enough support to meet their needs (1). People with autism and their families face different challenges at different stages in their lives; transition points can be particularly challenging. However, help is available, not only for the estimated 700,000 people living in the UK with the condition, but also for their families and carers. The National Autistic Society (NAS), the UK's leading charity for people affected by autism, provides a range of services and support. The charity operates a helpline staffed by autism experts who can offer advice on every aspect of autism, from diagnosis and education to employment support and adult services.

Introduction

Autism is a lifelong developmental disability affecting how a person communicates with and relates to others, as well as how they make sense of the world. While all people with the hidden disability share certain difficulties, the condition affects them in different ways. Some are able to live relatively independent lives but others have accompanying learning difficulties and need a lifetime of specialist support.

The NAS runs the Autism Services Directory (www.autism.org.uk/directory), a searchable database of autism-related services and programmes available in the UK. This includes support provided by the voluntary and statutory sectors, and is searchable by postcode or type of support.

Overview of support provided by the NAS

The NAS has nearly 20,000 members and around 100 branches run by volunteers. Each of these branches provides a local hub where parents, carers and people with autism can access help, support each other and meet other families in similar situations. The charity also provides the following.

- Information and advice for individuals and their families.
- Seven schools.
- Supported living and residential services for adults.
- Employment training.
- Outreach schemes.

Information and training is also available for health, education and other professionals working with people who have autism and their families. The continuation of these programmes and services is reliant on the charity's fundraising and its dedicated volunteers. Further information about all the support and services offered by the NAS is available on the charity's website: www.autism.org.uk.

What support is available?

Post-diagnosis and early years

A diagnosis can be a turning point for many families affected by autism, with a recent survey indicating that 58% of people thought their diagnosis helped them to access new or more support (2). However, it can also be an overwhelming and confusing time. Many parents do not know very much about autism when their child is diagnosed and yet are suddenly confronted with the reality of supporting a child and then later an adult with complex needs. Programmes like the NAS EarlyBird aim

to address these concerns, introducing autism to parents of pre-school age children with the condition and giving them the knowledge, confidence and abilities to develop their child's communication skills and cope with potential behavioural problems.

School-aged children

Children and young people with autism are entitled to extra help in school, college and university, as well as during times of transition and change. However, accessing appropriate support can be a very demanding and challenging process for parents of children with autism; recent research has shown that only 52% feel their child is making good educational progress (3).

Starting school or moving up to secondary school can make children with autism feel highly anxious but this can often be overcome through preparation and transition planning. It is therefore essential that they are aware of specialist support like the NAS Education Rights Service which can support parents to manage transition and access the right support. The service provides advice on all special educational needs issues, and can provide support with appeals to the SEN and Disability Tribunal.

Families can also access a variety of other programmes aimed at supporting school-aged children with autism.

- The Welfare Rights Service offers information and advice on benefit entitlements for children.
- The Community Care Service can help parents to find what support is offered by their local social services.
- EarlyBird Plus provides parents of children with autism aged between five and eight with an understanding of the condition and strategies to help them to support their children.
- The Parent to Parent Service is a UK-wide confidential telephone service run by trained volunteers who have their own children with autism and understand the impact the condition can have on families.
- The NAS EarlyBird Healthy Minds Programme promotes good mental health in primary-aged children with autism. It was developed following research showing that as many as 71% of children with autism have mental health problems, such as depression, and 40% have two or more (4). The programme was set up to pre-empt and prevent a large number of these problems from developing by training and licensing autism professionals to offer the programme to local families.

Adults and employment

Just 15% of adults with autism are in full-time paid employment, despite four out of five people with the condition saying that they would like to work, according to NAS research (5). People with autism can and do excel in a variety of roles but can experience great difficulty in finding and staying in employment, often due to inadequate support and misunderstandings related to their condition. Simple adjustments like making job interviews more accessible and providing support so that those in work understand the 'unwritten rules' of the workplace, can unlock the potential of a whole army of people with autism ready and willing to work.

The NAS provides training to organisations, employability professionals, and further and higher education staff who support people with autism into work. In Cardiff and Glasgow, the charity provides employment and training support for people with autism.

Support for professionals

There are thousands of professionals working for or with people with autism across the UK, in research, health, education, employment, local government or social care to name a few. Most recognise the complexity of the condition and accept the need for further training. For example, 80% of GPs indicate that they require additional guidance and training to identify and manage patients with autism more effectively (6).

The NAS works with autism experts to hold conferences throughout the year, sharing the latest research and examples of best practice with other professionals, as well as families and individuals

affected by the condition. Professionals can also keep up to date with developments in the field by signing up to Network Autism (www.networkautism.org.uk), a free online international community. Training is available from programmes like NAS EarlyBird and EarlyBird Health Minds, which licence autism professionals to go out into their own communities and offer sessions on autism and mental health directly to local families.

Conclusion

Without the right support, autism can have a profound, sometimes devastating effect on individuals, families and carers. Whilst support and services can be difficult to access, the voluntary sector does provide a range of guidance and services to support families to navigate every stage of the life of someone with autism, from early years and childhood right through to old age. Training programmes such as NAS EarlyBird provides direct support and training to parents and professionals while services including the Education Rights Service, the Welfare Rights Service and the Autism Helpline offer expert information and advice on specific topics. More information about NAS services is available on the charity's website: www.nas.org.uk.

GP Comment.

What I learned from this paper?

1. I found this a very useful article for signposting me towards the available services for parents of children with autism (NAS & the Autism Services Directory).
2. It is good to learn that NAS provides employment training - particularly in Glasgow.
3. Useful to learn of Network Autism website for professionals - I have signed up!

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GP, Glasgow.

References

1. The National Autistic Society (NAS) (2012). The way we are: Autism in 2012. London: NAS
2. Ibid
3. The National Autistic Society (NAS) (2008). Great Expectations. London: NAS
4. Simonoff E. et al (2008), Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity, and associated factors in a population-derived sample, *Journal of American Academy of Child and Adolescent Psychiatry* 47: 4: 921-929
5. Rosenblatt, M. (2008). I Exist: The message from adults with autism in England. London: NAS
6. National Audit Office (2008). Survey of General Practitioners in England on the subject of autism

Information and support resources

The National Autistic Society

The National Autistic Society's information on post diagnostic support:

For parents and carers:

<http://www.autism.org.uk/about-autism/all-about-diagnosis/diagnosis-the-process-for-children/after-diagnosis.aspx>

For adults with an autism spectrum disorder:

<http://www.autism.org.uk/about-autism/all-about-diagnosis/diagnosis-information-for-adults/after-diagnosis.aspx>

The National Autistic Society's Autism Helpline provides impartial, confidential information and advice for people with autism spectrum disorder and their families and carers.

Telephone: 0808 800 4104 (Monday to Friday, 10am-4pm)

Email enquiry form: www.autism.org.uk/enquiry

You can search for services and support in your area for people with an autism spectrum disorder, their families, and people who work with them, on the Autism Services Directory:

<http://www.autism.org.uk/directory>

Information on the National Autistic Society's services and schools can be found on their website:

<http://www.autism.org.uk/our-services>

The National Autistic Society has information specifically for professionals working with people with an autism spectrum disorder: <http://www.autism.org.uk/working-with>

Network Autism is an online community for professionals to connect and collaborate:

<http://network.autism.org.uk/welcome>

Research Autism

Research Autism is the only UK charity dedicated to research into autism treatments and therapies:

<http://www.researchautism.net/>

Training

Ask Autism is training developed and delivered by people on the autism spectrum:

www.autism.org.uk/askautism

Other online autism resources are listed on the RCN website:

<http://rcnpublishing.com/page/ns/resources/autism-online-resource-centre>

Online training for education professionals Inclusion development programme:
primary and secondary

<http://www.aet-idp.org.uk/>

Early Years Inclusion training:

<http://www.idponline.org.uk/eyautism/launch.html>

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We are very grateful to the National Autistic Society for providing the above information. Please also search for local autism support organisations. For example, in Bedfordshire, Autism Bedfordshire is available for local support, training and activities. In addition, we are grateful to Autism Bedfordshire for providing the cover photographs, which are reproduced with permission, and for being our partners in providing training courses for parents and professionals, organised by Jenny Wilson, Counselling Psychologist, SEPT.