

Frequently asked questions about the You Need To Know campaign

As part of The National Autistic Society's (NAS) *You Need To Know* campaign we are encouraging supporters to meet with their local MPs, commissioners and mental health professionals to tell them about the campaign and ask them to help us ensure that every child with autism and mental health problems can get the support they need.

We have produced three information sheets for supporters:

1. Meeting your Member of Parliament at their constituency surgery
2. Talking to mental health services about the *You Need To Know* campaign
3. Talking to mental health service commissioners about the *You Need To Know* campaign

This 'Frequently asked questions about the You Need To Know campaign' sheet goes with the information sheets and should help you prepare for any meetings. If you have any questions which aren't answered here, you can contact the NAS Campaigns Team to get more advice and information on campaign@nas.org.uk or call 020 7923 5799. Or visit the campaign website www.autism.org.uk/youneedtoknow

And remember that you don't have to answer any questions that you don't feel comfortable talking about. And if you don't know the answer, don't be afraid to say so. You can always tell the person you're meeting that you'll contact them afterwards to let them know the answer, or you can suggest they contact the NAS Campaigns Team themselves.

What is the You Need To Know campaign?

With the right support at the right time, children with autism can have good mental health just as anyone else can. *You Need To Know* is a new campaign by The National Autistic Society which aims to make this a reality.

The campaign is about recognising the contribution that individuals and services can make to promoting the health and happiness of children with autism, and preventing mental health problems developing in the first place.

It's also about ensuring that the over 70 per cent of children with autism who have a mental health problem get the support and services they need. Children with autism need the NHS to know how to help them through training for mental health professionals and access to specialist autism support in every area. The Government need to know it can't wait.

What is autism?

Some of the decision-makers and professionals that supporters meet will already know lots about autism, but others might not know very much. So if you're not sure, it's a good idea to ask the person how much they already know about autism at the start of your meeting.

Because autism is such a complex disability it can be hard to explain concisely, so you may find the explanation at www.autism.org.uk/autism useful. A brief explanation of autism could be something like:

Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people and the world around them. It is a spectrum condition, which means that, while all people with autism share certain areas of difficulty, their condition will affect them in different ways. Asperger syndrome is a form of autism.

You could also order a copy of our *What is autism?* leaflet from the NAS Information Centre by calling 0845 070 4004 or emailing nas@nas.org.uk It may also be useful to give examples from your own experience to help people understand better.

It's really important to emphasise that autism is not a mental health problem – it is a lifelong developmental disorder. When we talk about mental health problems in the *You Need To Know* campaign we are talking about conditions like anxiety, depression or obsessive compulsive disorder (OCD) which children may experience in addition to their autism.

Do all children with autism have mental health problems?

No. It's perfectly possible for children with autism to have good mental health, just as other children can.

Children with autism can be more susceptible to mental health problems because they can be socially isolated. They can struggle to make friends or could be bullied in school. They will often find it difficult to communicate their feelings when they are having problems or are feeling low, and so this can escalate. But with the right support at the right time, children with autism can have the same emotional well-being as any other child, and live happy, fulfilled lives.

Why should children with autism be a priority for reform of CAMHS?

Autism is a complex disability. When mental health problems do develop in children with the condition they are much harder to recognise, diagnose and treat without appropriate knowledge. For example, many therapies and interventions, such as cognitive behavioural therapy (CBT), rely on thought processes and communication techniques which do not make sense to children with autism and will not be effective without skilful adaptation. Frontline professionals themselves told the NAS that they wanted more training in autism. And 80 per cent of GPs, who would take on more responsibility for commissioning health services under the Government's proposals for reform of the NHS, also say they need more training in autism.

Children with autism already represent a substantial proportion of the people who use CAMHS (official statistics shows that 1 in 10 of the children who currently access CAMHS have autism), so it's essential that services work effectively for them.

The Government's health reform plans must include measures to ensure that the needs of children with autism and mental health problems are provided for. The National Institute for Health and Clinical Excellence (NICE) Quality Standards on autism should be developed, covering diagnosis, post-diagnostic support and support for those with co-occurring mental health problems, so that commissioners know what they need to provide for this group.

What do you mean by specialist services? What clinical evidence is there to show that this is what's needed?

By 'autism specialists' we are referring to the skills set that a professional has, rather than their professional qualifications or job title. We mean someone who can recognise and diagnose autism in children (or be involved in a multi-disciplinary autism diagnosis), can communicate effectively with children across the autism spectrum, can adapt the way they deliver mental health interventions to meet the needs of children with autism, and can support fellow professionals in working with children with autism.

The parents surveyed as part of The National Autistic Society research were twice as likely to say that CAMHS had improved their child's mental health when they felt that an autism specialist had been involved in their care. As part of the campaign, the NAS is also calling for more research into effective interventions for mental health problems in children with autism. NICE is currently considering new clinical guidelines on 'the management of autism spectrum disorders in children' and we will be calling on them to include providing effective interventions for children with autism and mental health problems within these guidelines.

How did The National Autistic Society carry out its research? Where do the statistics used in the campaign come from?

The finding that 71 per cent of children with autism have at least one co-occurring mental health problem is taken from a study by Emily Simonoff called "Psychiatric disorders in children with autism spectrum disorders", which was published in the *Journal of American Academy of Child and Adolescent Psychiatry* in 2008.

The finding that 1 in 10 of the children who access CAMHS have autism is taken from official children's services mapping by the University of Durham in 2009.

The National Autistic Society's own research, is a piece of social policy research, which reflects the experiences of parents and carers of children and young people with autism of using CAMHS, and the views of professionals who took part in the research. It is not a clinical piece of research into prevalence or specific interventions.

There were several elements of the research:

- qualitative discussions (focus groups and one-to-one interviews) with children and young people with autism who have experienced mental health issues, and their parents
- quantitative survey of CAMHS clinical directors in England – 47 of the 73 mental health trusts in England responded
- quantitative survey of parents of children and adolescents with autism who may have experienced mental health issues – 455 responses were received
- site visits to five CAMHS in England, where we carried out thirteen interviews with frontline professionals.

There is more information about the research methodology at the back of the campaign report (pages 52-54).

In the current economic climate, isn't it a difficult time to be campaigning for more services?

We know that 1 in every 10 children who use CAMHS has autism – that's over 10,000 children every year. And The National Autistic Society's research has shown that the services many are receiving are not working. So we need to use existing resources more effectively so that the services available can actually meet the needs of children with autism.

Some of our recommendations such as including autism within existing planning tools and involving parents and professionals in service planning are low-cost or cost-neutral, and should have been happening anyway. Furthermore, not having a clear pathway for accessing support can lead to further inefficiencies as children are referred to services which can't meet their needs, leading to delays in treatment and professionals spending time processing referrals which should have gone to another agency in the first place.

Although other measures would require more investment, particularly autism specialist services, if someone does not get the support they need, their problems are likely to escalate and become more complex, and therefore much more expensive to treat in the long term. Twenty-nine per cent of parents who responded to the NAS survey said that the mental health problems their children faced had led to other family members seeking support from mental health services for themselves, putting additional strain on NHS finances. Many families we spoke to also had had to reduce their working hours, thereby losing income and tax revenue. There are already examples of specialist services in some areas, demonstrating that it is possible to develop these within existing resources.