

Talking to mental health service commissioners about the You Need To Know campaign

This information is for anyone who wants to tell the people who commission local mental health services about The National Autistic Society's (NAS) *You Need To Know* campaign. Mental health services are commissioned by local authorities and primary care trusts (PCTs), which means that they decide how much money they are going to spend on Child and Adolescent Mental Health Services (CAMHS) and tell mental health service providers what services they want them to deliver.

In your local authority you might find it useful to contact the Lead Member for Children's Services (an elected councillor) or the Director of Children's Services (a officer who is not elected). In your PCT you could contact the Chief Executive or ask for the person who has overall responsibility for commissioning CAMHS. You may not get a meeting with these people, but they should pass your request on to another member of their team if they cannot meet with you themselves.

If you aren't sure who commissions mental health services in your area, the NHS provides a list of all the PCTs in England at www.nhs.uk/service directories/pages/primarycaretrustlisting.aspx and you can find your local authority at <http://local.direct.gov.uk/LDGRedirect/Start.do?mode=1>

The NAS has produced a FAQs sheet about the campaign which it might be useful for you to read before your meeting. You should also take a copy of the campaign report to give to the person you are meeting. You can order the report from the campaign website www.autism.org.uk/youncedtoknow or by contacting the NAS Campaigns Team, who can also give you any more advice or information you need (see contact details below).

What to tell local commissioners about the *You Need To Know* campaign

There's lots of information here about the campaign. However, if you have personal experience of using CAMHS, or are in contact with other people who have experiences of CAMHS that they are happy for you to share, even anonymously, don't forget to mention that too: it will demonstrate why the campaign is so important.

The NAS has carried out research with children and young people with autism, their parents/carers and frontline professionals to find out their views and experiences of CAMHS for children with autism and co-

occurring mental health problems. Based on this research, there are some key points that the NAS is making in its campaign:

- With the right support children with autism can have good mental health, as anyone else can.
- But as many as 7 out of 10 children do have mental health problems, and they are being let down by a system which cannot meet their needs. Two thirds of parents surveyed by the NAS said CAMHS had failed to improve their child's mental health.
- The NHS needs to know how to help children with autism: all CAMHS professionals need to have basic training in autism, and there should be specialist autism capacity in every PCT area.
- At a national level, the Government needs to make autism a priority area for reform of CAMHS.
- At a local level, we need commissioners to understand the needs of children with autism and mental health problems and to commission the right services for them.

Commissioners need to understand that 1 in 10 of the children who access their CAMHS is likely to have autism (this is based on official child health mapping carried out by the University of Durham). These children will need support from professionals who understand autism. Yet the NAS's research found too often CAMHS are providing interventions that are not working – two thirds of parents surveyed said that CAMHS had failed to improve their child's mental health. That means resources are not being used effectively, and more importantly it's a waste of children's lives.

Autism is a complex disability, and so children with autism who are experiencing mental health problems need to be treated by professionals who have a good understanding of the condition. That means commissioners need to make sure that all professionals working in CAMHS have at least received basic autism training, and that specialist autism support is available to all children and young people who need it.

We think that it would help commissioners to plan the right services if they had more information about who lives in their area and might need support, and about how existing services are working for children with autism and mental health problems. We also think they need to talk to experts – children and young people with autism, their parents and frontline professionals – to find out what they think is needed.

What commissioners can do to support the campaign

Here are some questions that you might want to ask commissioners about how they plan services and what services are available in your area:

- Do all of the staff working in your CAMHS have training in autism? If not, is this something that you are looking to address?
- Are there any specialist autism professionals working in the CAMHS in your area? If so, do they have enough capacity to deal with all the children with autism in your area who need support?
- Do you keep a record of how many children with autism are in your area? And do your records say how many of these children also have a mental health problem? If you do not do these things, how

do you make sure that you are planning the right services for the people with autism and mental health problems who live in the area?

- Are you able to compare the experiences of children with autism and their families compared to other children who are referred to CAMHS, for instance in terms of waiting times or outcomes?
- Is there a specific pathway for mental health support for children with autism so that everyone knows what support is available locally and how to access it?
- Do CAMHS provide any 24-hour services for people who need support at a time of crisis? If so, what are they?
- Do you involve young people with autism and their families when you are planning local CAMHS? If so, how?

It's unlikely that commissioners will be able to address all of these issues at once. So a good first step would be to ask them to agree to meet with you again to discuss these issues further. You could ask if other people affected by the issue can also be involved in that meeting, including mental health professionals.

If commissioners want more information or have any questions about the campaign that you can't answer, you could suggest they visit the campaign website www.autism.org.uk/youneedtoknow or contact the NAS Campaigns Team (see contact details below).

Support for professionals

Commissioners may also be interested to know about the resources that the NAS is producing to support CAMHS professionals in working with children with autism and mental health problems. These include:

- a guide for CAMHS professionals which will be available from the autumn
- a Happiness Heroes scheme highlighting good practice by individual professionals and services in improving the health and emotional well-being of children with autism – there are also some examples of good practice in the campaign report and we'll continue to look for opportunities to highlight more as the campaign goes on, so that it can be replicated in other areas
- online resources, such as an online discussion group for professionals to share experiences and advice and interviews with CAMHS professionals who have experience of working with children with autism on the NAS website later this year
- a CAMHS conference in 2011 for people working and involved in the development of mental health services.

The Department of Health has also commissioned a number of training resources for health and social care professionals in response to the adult autism strategy and some of these will be useful for CAMHS and other children's services staff. These will be published by the end of the year, and will include resources from the British Psychological Society and the Royal College of Psychiatrists.

After your meeting

It's a good idea to write to commissioners after your meeting, thanking them for taking the time to see you and confirming what they agreed to do.

Please also contact the NAS Campaigns Team to let us know how it went. You can contact us by emailing campaign@nas.org.uk or calling 020 7923 5799.