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# YOU NEED TO KNOW

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The National  
Autistic Society

Accept difference.  
Not indifference.



**THOUSANDS OF CHILDREN WITH AUTISM FACE A FUTURE OF MENTAL HEALTH PROBLEMS. NEEDLESSLY.**

**WE CAN CHANGE OUR CHILDREN'S FUTURE.**

**Children with autism need:**

- **the NHS to know how to help them**
- **the Government to know this can't wait.**



Some people may find the experiences described in this report disturbing. If you would like to talk to someone about any of the issues raised in this report, you can call our Autism Helpline on 0845 070 4004 (Monday to Friday, 10am to 4pm) or our Parent to Parent support line on 0800 9 520 520. If you need out-of-hours support, you can call SANEline on 0845 767 8000 (6pm to 11pm), the national telephone helpline offering emotional support and information for people affected by mental health problems.

## Acknowledgements

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With thanks to NAS staff Adél Schofield, Beth Reid, Chris Lean, Matthew Downie, Amanda Batten, Serena Shah, Sarah Redman, Lisa James, Sarah Best, Sarah Lambert, Anna Ostmeier and Cathy Lloyd.

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# Contents

Executive summary	4
Autism and mental health: what's the issue?	6
The journey through CAMHS: from referral to transition	14
Better understanding of autism in the system	22
More autism specialism needed in the system	32
Planning the right services	40
Conclusion	50
Summary of recommendations	51
Research methodology	52

Written by Tom Madders

All case studies of children with autism in this report are as reported by parents. To protect their identities, no case studies except 'Tim' use real names, and all photographs in the report use models.

# Executive summary

- Just one third (32%) of parents believe that CAMHS have improved their child's mental health.
- Less than half (46%) of parents think CAMHS staff know how to communicate with their child.
- Parents are twice as likely to say that CAMHS have improved their child's mental health when they report that an autism specialist has been involved in their treatment.
- 44% of parents find it difficult to get a first referral to CAMHS for their child, with a quarter waiting over four months for a first appointment following referral.

**Autism<sup>1</sup> is not a mental health problem. But a recent study showed that as many as 71% of children with autism have mental health problems, such as anxiety disorders, depression, and obsessive compulsive disorder (OCD), and 40% have two or more<sup>2</sup>.**

It doesn't have to be like this. With the right support from people who understand how to support them effectively, children with autism can have perfectly good mental health, just like anybody else. However, when mental health problems do develop, we need to make sure that the right services are there to help these children and their families.

Child and Adolescent Mental Health Services (CAMHS) are the NHS services that exist to support all children with mental health problems and their families. But too often these services cannot meet the needs of children with autism. The impact of a lack of support can be devastating for the whole family, often leading to social exclusion and reduced working hours for parents.

Over the past year, we have carried out in-depth research with children, parents and professionals to find out why this is the case and how CAMHS services can work better for children with autism. We uncovered a service that frustrates both its providers and its recipients.

## These are the facts you need to know:

### CAMHS professionals need to understand autism

- Professionals told us that many of their colleagues had not had basic autism training, meaning that they could not treat mental health problems in a child with autism.
- Parents told us how they regularly came across professionals who did not understand autism or how to communicate with their child, leading to inappropriate and ineffective treatment of their mental health problems.

<sup>1</sup>The term autism is used throughout this document to refer to all people on the autism spectrum including Kanner autism, Asperger syndrome and high-functioning autism.

<sup>2</sup>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

<sup>3</sup>Wistow, R. and Barnes, D. (2009) A profile of child and adolescent mental health services in England 2007/8: findings from children's services mapping, Durham University, Department of Health, Department of Children Schools and Families



**“She needed some really specific help at that point, you know? She wanted to die and all they could do was tell us that we were bad parents. Even if we were, even if we still are, that's not the issue at hand. The issue's that you've got a child here that isn't coping. What are you going to do about it? They had no way of helping her whatsoever.”**

**Parent of teenage child**

### Outcomes and experiences improve significantly when an autism specialist is involved

- Professionals told us about the complex and specialist knowledge that was needed to adapt treatments so that they worked for children with autism.
- The experiences of parents and the perceived outcomes of children were vastly improved when they reported an autism specialist had been involved in the service they received.

### The right support needs to be planned locally

- Many parents told us that they had to wait inordinate lengths of time to be seen by CAMHS, with some being turned away because nothing suitable existed for them in their area.
- Professionals explained how commissioners did not have a good enough understanding of how many children with autism were accessing or waiting to access CAMHS, or that they often need autism-specific support, so they did not commission the right services.

**1 in 10 of the children who use CAMHS have autism<sup>3</sup>, but too many are being let down. This needs to change.**

**Thousands of children with autism face a future of mental health problems. Needlessly.**

**We can change our children's future.**

**Children with autism need:**

- the NHS to know how to help them
- the Government to know it can't wait.

**For a full list of recommendations please see page 51.**

# Autism and mental health: what's the issue?

- 71% of children with autism have at least one co-occurring mental health problem, while 40% have two or more<sup>4</sup>.
- 1 in every 10 children who access CAMHS has autism<sup>5</sup>.
- Just one third (32%) of parents of children with autism believe that CAMHS have improved their child's mental health.
- 9 out of 10 parents told us that the mental health problems faced by their child had had a negative impact on their own mental health (88%) and on the family as a whole (91%).

**Autism is not a mental health problem. It is perfectly possible to have autism and very good mental health, just as this is possible for anybody else.**

But far too many children with autism go on to develop mental health problems. We know that while one in 100 children has autism<sup>6</sup>, more than seven in ten children with autism also have a co-occurring mental health problem<sup>7</sup>. Many of these problems are entirely preventable, with the right support. It's clear that more needs to be done to stop them from occurring.

Unfortunately, once these mental health problems develop, children with autism aren't getting the necessary support from Child and Adolescent Mental Health Services (CAMHS) – the NHS services that are designed to help them.

When the right support is not provided at the right time, the impact on these vulnerable children and their families can be devastating. The *You Need To Know* report investigates the impact of mental health problems on children with autism and their families. The report focuses on how the CAMHS system isn't meeting their needs and what can be done to improve the outcomes and experiences of these families, while recognising the wider responsibility of other agencies to promote the emotional wellbeing of this group.

## What's the difference between autism and mental health problems?

### Autism

Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people and the world around them. Autism affects 1 in 100 people. It is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in different ways.

There is no known cure for autism. Some people with autism are able to live relatively independent lives but others may need a lifetime of specialist support. The main areas of difficulty are in recognising and understanding other people's feelings and managing their own, using and understanding verbal and non-verbal language, understanding and predicting other people's intentions and behaviour and imagining situations outside of their own routine. People with autism may also experience over- or under-sensitivity to sounds, touch, tastes, smells, light or colours.

### Mental health

Most of us will experience issues with our mental health at some point in our life, perhaps related to how we feel about ourselves or the way that we handle our emotions. These difficulties can become mental health problems when they begin to affect our life in a negative and ongoing way. For example, when a person feels overwhelmingly sad or worried for a sustained period of time, this can develop into conditions such as depression or anxiety disorders.

Other psychiatric conditions which can affect children with autism include attention deficit hyperactivity disorder (ADHD), obsessive compulsive disorder (OCD) and bipolar disorder. Unlike autism, such conditions are treatable using psychiatric interventions, so we term these conditions mental health problems.

Sometimes it can be difficult to tell how a person with mental health problems is feeling – but if the person also has autism they may find it even more difficult to express themselves. Some may not even be able to speak. There are, however, other non-verbal ways in which people may communicate how they feel, such as through changes in their behaviour.



<sup>4</sup>Simonoff E. et al (2008). Op cit.

<sup>5</sup>Wistow and Barnes (2009). Op cit.

<sup>6</sup>Baird, G. et al (2006), 'Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP)', *The Lancet*, 368 (9531), pp210-215

<sup>7</sup>Simonoff E. et al (2008). Op cit.; Leyfer et al (2006) Leyfer, OT, et al (2006) Comorbid psychiatric disorders in children with autism: interview development and rates of disorders *Journal of Autism and Developmental Disorders* 36: 849-861

## Why are mental health problems so common among children with autism?

Research has demonstrated that 71% of children with autism develop mental health problems like depression, anxiety disorders, attention-deficit hyperactivity disorder (ADHD) and OCD (see figure 1)<sup>8</sup>. This compares to a prevalence rate of around 10% in other children<sup>9</sup>.

These findings are reflected in our own research, not only by parents of children with autism, but also by the overwhelming majority of clinical directors, who reported seeing ADHD, clinical depression, anxiety disorders and OCD occurring in children with autism at their CAMHS. Conduct disorder, Oppositional Defiant Disorder and psychosis were also cited by most clinical directors.

The parents we surveyed reported that their children's mental health problems were developing at very young ages. 4 out of 5 parents (83%) told us that their children first experienced these issues before the age of ten, and half (47%) before the age of five, (see figure 2).

When we asked parents what things affected their children's mental health in a negative way, the most common answers related to not getting the right support for their autism and professionals not having enough understanding of the condition.

Children with autism find it very difficult to understand the world around them. They may not understand social cues and expectations, or be able to identify the patterns and routines in their lives. Help with understanding what to do in different situations, what happens next in a sequence of events, or coping with changes in routine can make a big difference. But without such support children can become very anxious or frustrated.

Children with autism are also less likely to have strong social relationships than other children. One study found 42% of children with autism had no friends, compared to 1% of other children<sup>10</sup>. They may act in unusual ways, or try to fit in with their peers but do it in socially inappropriate ways. In some cases other children may ridicule or bully them as a result.

Difficulties at school and elsewhere may affect children's self-esteem. An inability to express their own feelings can lead to escalating emotions or being unable to deal with experiences such as loss or grief.

### Our research<sup>11</sup>

The National Autistic Society carried out quantitative and qualitative research, covering parents and children affected by the issue, and professionals working in the field. This included a questionnaire about the experiences of children and young people with autism and their families, via parents and carers. A total of 455 eligible responses were analysed.

Of the children for whom we received responses about, the majority (73%) were male. The most common autism diagnosis was Asperger syndrome and high-functioning autism (43%), with ASD/autism (26%) and autism with a learning disability (12%) also common.

The most commonly reported mental health problems that the children had experienced were anxiety (85%), behavioural issues including defiance and non-compliance (62%), depression (36%), self-harm and self-injury (33%), suicidal thoughts (27%) and Obsessive Compulsive Disorder (21%).

## Prevalence of mental health problems in children with autism

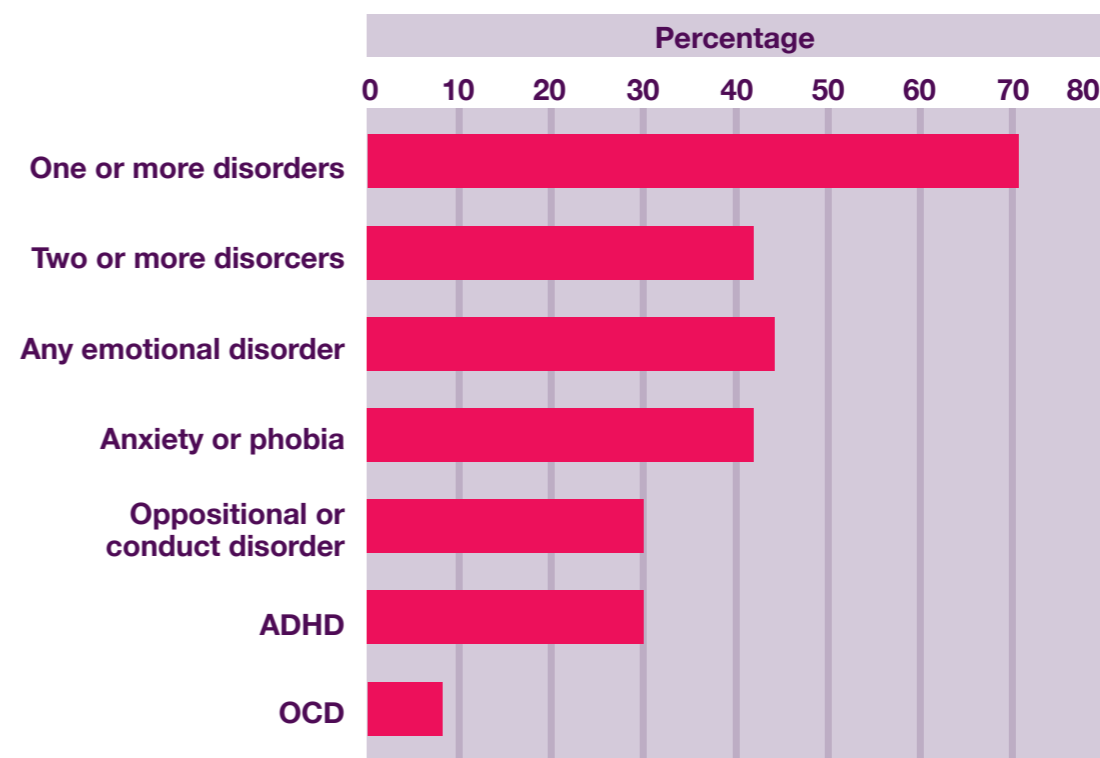


Figure 1: From Simonoff et al (2008), table 1. Emotional disorders include anxiety and phobic disorders and mood disorders (such as depression).

## At what age did your child first experience a mental health problem?

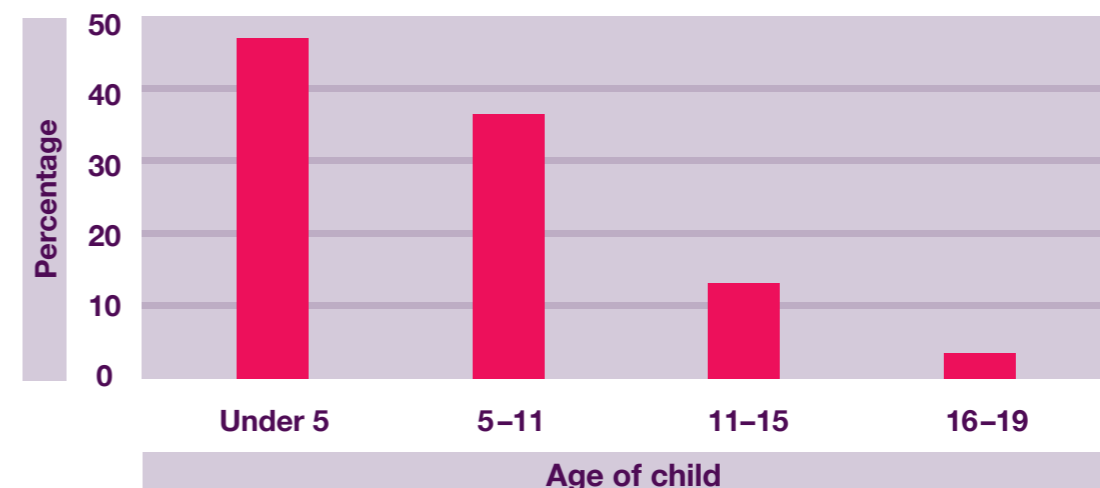


Figure 2: Based on responses from 435 parents of children and young people aged 0-21 who reported that their children had experienced mental health problems, survey conducted by the NAS in January 2010

<sup>8</sup>Simonoff E. et al (2008). Op cit.

<sup>9</sup>Green, H., McGinnity, A., Meltzer, H., et al. (2005). Mental health of children and young people in Great Britain 2004. London: Palgrave.

<sup>10</sup>Green et al (2005). Op cit.

<sup>11</sup>For full research methodology please see page 52

## Case study: West of Cornwall CAMHS

West of Cornwall CAMHS has forged strong links with the educational institutes in its area. The team receives a lot of referrals from schools, with the rest coming from primary health visitors, school nurses, social care services or from families themselves through their open referral policy.

The team have structured their catchment area into six districts, with around five schools in each district. They now have a presence in all of these schools.

CAMHS staff regularly attend the school's multi-agency meetings to maintain and strengthen the relationships they have with the schools. They have a joint service with behaviour support teams and with the schools' autism advisors, thus allowing a part of CAMHS to work exclusively with each school.

"...a part of our service works almost exclusively within the school, so when we pop up we're not seen as alien, we're just seen as another person that works with behaviour support, for example..."

*Clinical team manager*

It is the norm for CAMHS staff to be present at school meetings, and this familiarity allows the schools to feel comfortable enough to contact CAMHS about any arising issues. It also allows CAMHS to work with the school in the ongoing assessment of a child.

Within the CAMHS team there are individuals who are autism specialists. They also have a social communication advisor who works specifically with children with autism at schools.

This close working link with each school facilitates a multi-disciplinary approach to treating children with autism and mental health problems and can also help eliminate some of the difficulties that arise from a school's lack of understanding of autism. It also keeps some routine in the child's life, which can help to lower anxiety and increase the success of their treatment.

A supportive educational setting which works for the child, in partnership with mental health services, can be crucial both in maintaining emotional wellbeing and preventing mental health problems from developing. Yet our own research from 2006 found that 34% of parents said that a delay in accessing the right support at school had a negative impact on their child's mental health<sup>13</sup>. The same study found that 50% of children are not in the kind of school their parents believe would best suit them. We also know that 1 in 4 children with autism have been excluded from school, with many being excluded multiple times<sup>14</sup>.

Awareness and consideration from the general public also plays its part. Whether in shops or restaurants, on public transport or in the park, children with autism and their parents can face intolerance and a lack of understanding from others that can cause considerable stress and anxiety. In a recent survey, 83% of people with Asperger syndrome felt strongly or very strongly that many of the problems they faced were as a direct result of others not understanding them<sup>15</sup>.

**"School was a disaster, it caused him lots of mental health issues. He had really low self-esteem and he was bullied."**

**Parent of a young child<sup>12</sup>**



Under these circumstances, it is easy to imagine how mental health problems in one or more children can also have an impact on the rest of the family, especially when the right support is not in place.

Nine out of ten parents (88%) told us that the mental health problems their children faced had had a negative impact on their own mental health, and a similar proportion (91%) said that it had led to a negative effect on the mental health of the family as a whole.

Three quarters (74%) of parents who say there has been a negative impact on the family said that they see less of their friends and wider family. Two-thirds (65%) say that they do not go out as a family as much or at all, and three-fifths (61%) say that they have less time for their other children. Mental health problems can also have a financial impact, with over half (56%) of parents having to reduce their working hours. It is not then surprising that 29% of parents say that they and other members of the family (apart from the child with autism) have needed support from mental health services.

"It has just been a complete nightmare for three years... I'm surprised I'm still here, because of the times I've felt like throwing myself off the motorway bridge."

*Parent of a young child*

Of course, it does not have to be like this. With the right support from people who understand how to support children with autism and their families, many of these difficulties can be overcome. Children with autism can live happy, healthy, fulfilled lives, do well at school and reach their full potential. But it is up to all of us to do what we can to make this happen.

**"The things that have improved in that last year just show me that the contact with the school and the way that they handled his behaviour has been a really good experience for him. Now he wants to go back to school, he's feeling confident. He wants to go back to socialise and meet some new friends."**

**Parent of teenage child**

<sup>12</sup>A 'young child' in this report is a child aged 10 or under

<sup>13</sup>Batten A. et al (2006), Make School Make Sense, National Autistic Society

<sup>14</sup>Green et al (2005). Op cit.

<sup>15</sup>Beardon, L and Edmonds G (2007). ASPECT consultancy report: a national report on the needs of adults with Asperger syndrome, Sheffield Hallam University



## The role of Child and Adolescent Mental Health Services (CAMHS)

In our survey of parents of children with autism, only 37% were satisfied with the service they received from CAMHS. And the frustrations of these parents are echoed by the frustrations of professionals who want their CAMHS to provide the best possible support to children with autism.

We also found that just 32% of parents believed that CAMHS had improved their child's mental health. So what's going wrong?

Difficulties arise because autism complicates things. It is a complex disability which makes it harder to diagnose mental health problems in children when they develop. It can also make it more difficult for professionals to develop successful, trusting relationships with children. Support almost always needs to be adapted towards the child and their autism. Mainstream interventions and treatments, unadjusted, will usually fail to improve the mental health of a child with autism. They can even make things worse.

Throughout this report, we will see how it often takes specific autism expertise to be able to diagnose mental health problems in children with autism, to develop successful relationships with the child and to make those adaptations to support. Our research found that when parents told us an autism specialist had been involved in the support their child had received for their mental health problems, they were twice as likely to say that CAMHS were able to communicate with their child, twice as likely to be satisfied with the support they received from CAMHS and twice as likely to say that CAMHS had improved their child's mental health<sup>16</sup>.

Children with autism are certainly not uncommon in the CAMHS system – one in ten children who access CAMHS has autism<sup>17</sup>. Despite this, nine out of every ten CAMHS do not provide any targeted support for children with autism<sup>18</sup>. Specialist autism expertise must be available to all children with autism and mental health problems wherever they happen to live, and CAMHS professionals must have a good enough understanding of autism to identify and support these children and make appropriate referrals to specialists where necessary.

**“[My son] started having problems when he went to secondary school. He said he would rather be dead, so we were quickly referred to CAMHS... For the last four years we've been under them, we've tried a variety of things. They're very helpful, very supportive, great to talk to, but they don't seem to have any ideas of what to do. He doesn't fit into their general remit, he's too specialised [for them].”**

**Parent of teenage child**

## Direction from Government can make a huge difference

An understanding of these issues must not begin and end with frontline professionals. Their dedication to providing the right support is all too often restricted by a lack of resources. Those who plan and commission local services must recognise the need to commission support that meets the needs of children with autism and mental health problems. And crucially, the new Government must recognise children with autism as a priority for service improvement in CAMHS and support local areas to deliver the change that families and frontline professionals are crying out for.

Government initiatives can make a dramatic difference to service delivery. Over the past few years, services for children with a learning disability have been recognised as a national priority<sup>19</sup> and the impact of this is plain to see: while research shows that 65% of CAMHS teams support children with autism, only 10% of CAMHS teams report that they provide targeted support<sup>20</sup> to this group. In contrast, 69% of CAMHS teams offer specialist provision for children with a learning disability. Two years previously (in 2005) this figure had been 33%<sup>21</sup>.

The number of children with a learning disability in the CAMHS system is identical to the number of children with autism (9%)<sup>22</sup>.



While there is still a very long way to go to improve services for children with a learning disability, we can at least be sure that those services are available to a far greater number of children and their families than they were previously.

Frontline professionals have identified a similar need for improvements to services for children with autism at a local level, and have told us that Government action is required to ensure that commissioners respond to this.

We recognise that some children with autism also have a learning disability, but this does not change the fact that they need support that recognises and understands their autism. We need to see the same level of national priority given to improving services for children with autism as has been given to children with learning disabilities.

**“We all have three different commissioners and nobody has taken the lead for autism.”**

**Specialist Occupational Therapist**

<sup>16</sup>See chapter: 'More autism specialism needed in the system', page 32

<sup>17</sup>Wistow and Barnes (2009). Op cit.

<sup>18</sup>Wistow and Barnes (2009). Op cit.

<sup>19</sup>See page 44: "How Government initiatives have increased provision of learning disability services"

<sup>20</sup>This statistic is derived from the following question asked to CAMHS teams by Durham University: "Does any part of your service/team provide targeted work with the following groups?" (ASD being one of those groups)

<sup>21</sup>Wistow and Barnes (2009). Op cit.

<sup>22</sup>Wistow and Barnes (2009). Op cit.



# The journey through CAMHS: from referral to transition

- 44% of parents found it difficult to get a first referral to CAMHS for their child.
- A quarter (25%) of parents waited over four months for a first appointment following referral.
- 4 out of 5 (80%) parents say that there have been times of crisis with their child's mental health when they needed support, but the majority of these parents were unable to access that support.
- 70% of parents of 14-17 year-olds say that no transition plan is in place for when their child becomes too old for CAMHS, and 92% worry about what support their child will receive as an adult.

**Children with autism and their families can experience problems with CAMHS at any stage. For many, the problem is simply accessing the service in the first place. 44% of parents found it difficult to get a first referral for CAMHS for their child. Some of the parents we spoke to had waited two or three years for a referral.**

Parents are often confused about how to access the system, despite being desperate for support. This chapter follows the journey through CAMHS, from getting a first referral through to the final transition to adulthood. It also demonstrates the importance of providing the right support for families in times of crisis.

“His self-harming is off the scale. I mean I’m talking about slamming his head on anything and if he can’t find anything hard, he’ll start on his arms. If you stop him from that, then he’ll start on you. A couple of years ago my arms were a mess with bruises, bite marks and scratches... CAMHS just didn’t want to know when he was at his self-harming peak ... My husband had to threaten to go to the local papers. He took photographs and he sent them to the paediatrician and he said to her, ‘If you don’t refer him to CAMHS regarding the self-harming and the fact he’s attacking me, my wife and my two daughters, if you don’t do it, then we will go the papers...’ A week later they decided we could get a CAMHS appointment.”

*Parent of a teenage child*

**“CAMHS have closed to new referrals because they’ve got too much workload... so what do I do with this child?”**

**Parent of a young child**

## What are Child and Adolescent Mental Health Services (CAMHS)?

The term CAMHS in its widest sense refers to all services that contribute to the mental health care of children. It can also be used to refer to specialist mental health services for children and young people. Universal services like schools, GPs and social services are referred to as ‘tier 1 services’. These services play a crucial role in the emotional wellbeing of children, but when we refer to CAMHS in this report we are talking about specialist mental health services, i.e. CAMHS tiers 2 to 4. Tier 2 consists of mental health specialists working in primary care and community settings, such as psychologists and counsellors working in GP practices, paediatric clinics or schools. Tier 3 generally refers to multi-disciplinary mental health teams providing a dedicated service to children with complex, severe and persistent mental health problems. Tier 4 provides services for children with the most serious or complex problems, for instance inpatient units or highly specialised outpatient teams.

## Waiting times

Following referral, a quarter (25%) of parents waited over 18 weeks for their first appointment and a further 10% waited between 13-18 weeks. On getting their first appointments, some had to begin the referral process again after an unsuccessful initial meeting with CAMHS led staff to conclude that no treatment was necessary. Others complained of a ‘revolving door’ situation, where their children were given short, episodic interventions of six to eight weeks and were then discharged regardless of whether progress had been made. Following discharge, the whole referral and waiting process had to start again.

“She said, ‘I couldn’t assess him because he wouldn’t cooperate’. I was signed off.”

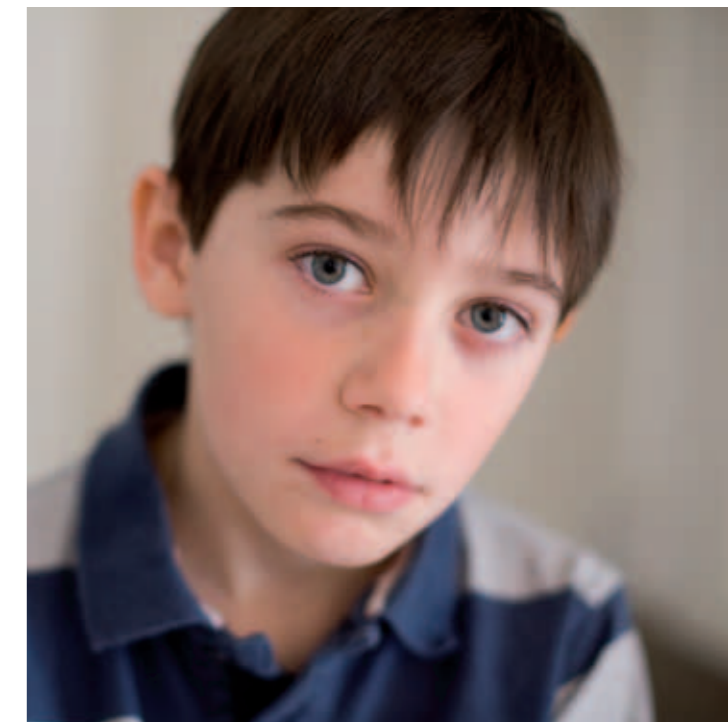
*Parent of a young child*

**“I wrote a letter to the Community Paediatrician saying ‘I’m sorry, it’s not acceptable, it’s not my fault that CAMHS are overworked. I have this child at home. I now have a baby as well. I’m frightened he’s going to kill her because he got so aggressive.’ I just kept ringing up.”**

**Parent of a young child**

“If they say it’s a problem but it’s not a crisis, then they can fester for some time before they get seen.”

*CAMHS Clinical lead for ASD crisis intervention*



## Case study: Flockton CAMHS team, Sheffield

The Flockton CAMHS team have a multi-disciplinary clinic called the Attention, Behaviour and Communication Clinic for children with autism and/or ADHD. It was noticed that children waiting for autism-specific support were waiting longer than other children for assessments from CAMHS. The clinic had limited capacity with just one psychiatrist and one psychologist to carry out assessments, with input from an ADHD nurse. The assessment process was subsequently streamlined by bringing in additional clinicians from other CAMHS teams to provide extra support and expertise as and when it was needed. The team also tightened the screening criteria for diagnosis to save time. This has substantially reduced the waiting time for children with autism and mental health problems waiting to use the clinic.

## Crisis intervention

Some parents of children with autism and mental health problems regularly find themselves in emergency situations where they need urgent, immediate support. This is particularly true of children who are challenging or aggressive towards other family members, who self-harm or attempt suicide. When crises arise, families tell us that they need support in the form of on-call home visits (73%), emergency appointments (65%) and a 24-hour helpline (64%).

Emergency support from CAMHS has been a target for Government improvement over the past few years, and more and more CAMHS are reporting that they provide 'on-call services' and emergency support<sup>23</sup>. But despite this, very few of the CAMHS teams that we spoke to provided any emergency, on-call support in their areas. A couple of professionals told us that urgent cases are seen within a week or two of referral. But when a child is threatening themselves or family members and support is needed immediately, this response is simply inadequate. It leaves families having to call the police, who are not trained to support children with such complex needs through a traumatic episode. This is completely inappropriate and incredibly frightening for a child who is already experiencing severe mental health problems, particularly when they have autism and find it difficult to cope with unfamiliar people and situations.



**“After he set fire to himself, I talked to the hospital. [He was] admitted by the casualty doctor onto a ward. The ward wouldn't accept him because it wasn't the right person because he didn't have training in Asperger's or mental health. So we were put on a ward that was actually closed and left there for hours and hours and hours.”**

Parent of teenage child

This situation is reflected by the experiences of parents. 4 out of 5 (80%) parents told us that there have been times of crisis when they and their family have needed to access local CAMHS, but only a quarter (24%) of these families were able to get the emergency support they needed. This is not just a problem for children with autism, but for many other children with serious mental health problems.

“We had the mental health services round who sat at the kitchen table and interviewed him for a while and said they didn't think that they could offer him anything. He said, 'But don't worry, you can come back to us. If there's a crisis, come back to us' and I said, 'Oh what, that means you'll come immediately?' 'Oh no, there'll be a waiting list. About six weeks'. Off he went. It's just ridiculous.”

Parent of a young adult



“They are not very good if there is a crisis. They don't know what to do. I was left with a child who was cutting her arms and smearing blood all up the walls, locking herself in a room. So I changed all my doors so that they opened outwards so she couldn't lock herself in a room. I had to keep any form of medication, any razor blades, absolutely anything. I used to lock them in the glove compartment of my car, so she couldn't get hold of them, keep the keys on me, so that she couldn't get hold of anything. She is very inventive and for something that she picked up in a few days, it took us months and months to stop her doing it. CAMHS didn't help us do that. They gave no advice on anything... You're just stuck on your own and you've got to deal with it.”

Parent of a young adult

**“During the daytime there isn't anything dedicated for crisis. So, if anyone has a crisis they've got a choice of who they ring; GP, A&E, police.”**

Clinical Director

<sup>23</sup>Durham health mapping (Wistow and Barnes (2009). Op cit) showed that only 2% of NHS providers reported no on-call services, protocols or plans in place. A further 4% of NHS providers had plans and protocols but no services in place, 34% had some on-call services in place with some still to be developed and 61% had a fully comprehensive on-call service available.

The following is an excerpt from a real letter to CAMHS as part of an ongoing attempt to access emergency provision from CAMHS. The family was receiving no support from CAMHS at the time, and this letter received no response.

Dear [name removed]

#### ***Attempted Suicide***

On Saturday I discovered [my son] attempting to hang himself again. He had tied up the dog's lead to banisters and was starting to suspend himself by it. He gave up when I informed him I would cut him down and revive him when he lost consciousness. He was not happy with my intervention.

His depression was increased because he could not arrange to see any of his friends at the weekend.

#### ***Attack on Mother***

On Sunday morning he was looking forward to going out for the day with his mother to a country fair. After eating two scones for breakfast he became very agitated and accused [my wife] of forcing him to eat. He then went to pick up the kettle which had just boiled. My wife thought he was going to throw it over her and tried to run but fell badly, [my son] then overpowered her and attempted to force bread in her mouth. [My wife] finally fought him off but was badly shaken.

She then refused to take him to the fair. [A consultant] said we were too lenient with him when he misbehaved and we should set boundaries and stand up to him. I returned from walking the dog and found both [my wife] and [my son] in an emotional state. [My son] spent the rest of the morning alternatively crying and demanding he should be taken out or should be allowed to hang himself. Later in the morning he was overcome by a fit of anger and punched [my wife] in the back, which badly hurt her. He continued in this state until noon (without indication that he would/could calm down) until I finally agreed to take him out and give [my wife] a break.

We must make sure that CAMHS emergency or on-call services are doing what they are there for. Adequate crisis provision must be defined in terms of what families want and need, or else those families will remain unsupported at their times of greatest need.

## We recommend

**that the Government amends its definition of emergency CAMHS provision to better meet the needs of children and families.**

**that commissioners ensure that local CAMHS have the capacity to provide 24-hour support to children and families who need it.**

## Support for families

The remit of CAMHS includes support for the whole family. That support might be through family therapy sessions<sup>24</sup>, or could be through advice and coping strategies to help family members deal with their child's mental health problems at home and to help them to recognise signs of poor mental health in themselves.

When the whole family are supported and involved, it can enable them to continue caring for their child, to contribute to the child's recovery and prevent family breakdown. But just one third (33%) of parents agreed that CAMHS had provided for other members of the family who had needed support. It is crucial that the Government recognises the impact that mental health problems in children can have on a family, and that commissioners recognise CAMHS' responsibility to support the whole family, not just the child.

## Transition to adulthood

“When I went up to adult services, [the psychiatrist] actually came with us to help with the changeover. So we had this great big discussion about how we could make it easier for me moving up, because obviously all this history with people, it's just terrifying for me to meet another doctor. We wanted to make it simple. It was helpful, I think.”

*18-year-old woman*

Moving into adulthood is a very important time for all disabled young people who receive statutory services, but for young people with autism it is especially so. People with autism find coping with change intrinsically difficult, so the multiple changes involved in their transition are always a significant challenge.

The transition process can be made easier through good communication between children's and adult services, with plans being developed from an early stage. It is therefore worrying that for many children with autism and mental health problems, transition planning simply is not happening. The vast majority (84%) of parents of children aged 14-17 told us that their child requires ongoing mental health support. Most of these parents and parents of 18-21 year olds requiring ongoing mental health support said that there was no plan in place to determine what support their child would receive when they got too old for support from CAMHS (70%). Almost all parents (92%) worried about what mental health support their child would get when they turned 18.



<sup>24</sup>Family therapy is a therapeutic intervention in which the family is treated as a whole, identifying helpful family strategies and working with family members whose own mental health may have suffered.

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“The lady at CAMHS kept everyone together, but everything was lost completely through the transition phase. She had meetings with the adult teams and got absolutely nowhere. As soon as it stopped, as soon as she was out of the picture, everything went to pieces.”

*Parent of a young adult*

Most of the CAMHS teams we spoke to did not routinely plan for transition to adult services, and lacked any kind of formal protocol for dealing with transition. Those who did take steps for a smooth transition to adulthood often found it very hard to get adult mental health services to buy into the process, as they would not plan support for anyone who was not presently eligible for their service.

Our previous research has found high levels of mental health problems in adults, too. One third (33%) of adults with autism told us that they have experienced serious mental health problems because of a lack of support<sup>25</sup>, further demonstrating the need for services to be put in place for their transition to adulthood.

**“I would start thinking about transition from fourteen plus, but it is very hard to get social care and adult mental health involved at that age. In fact, it is almost impossible. I tried to plan the onward move of people with autism and learning disabilities from residential school to adult placement, and it looks to me like a complete lottery. There is almost no planning involved at all. It all seems to be done as a crisis, rather than in a planned way.”**

**Clinical Psychologist**



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## We recommend

**that the forthcoming statutory guidance on services for adults with autism must include duties around transition in mental health services.**

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<sup>25</sup>Rosenblatt, Mia. (2008) I Exist: The message from adults with autism in England. London: The National Autistic Society

# Better understanding of autism in the system

- Only half (52%) of parents feel that CAMHS staff have a good understanding of autism.
- Less than half (46%) of parents think that CAMHS staff know how to communicate with their child.

**Autism is a complex disability. When mental health problems arise in children with autism these problems are harder to recognise, harder to evaluate and harder to treat. Professionals need a good working knowledge of autism in order to do these things, or the interventions they provide can fail to help, and in some cases will be harmful.**

“[In working with children with autism, colleagues] do not generally feel comfortable... They don't get enough experience of children with autism in general.”

*Clinical psychologist*

“[CAMHS] actually have no detailed knowledge of autism. I assumed that they would know far more about it than I did. I assumed they would be able to guide me as a parent. I assumed that they'd be able to help.”

*Parent of a teenage child*

Only half (52%) of parents feel that CAMHS staff have a good understanding of autism. Many professionals also tell us that they or their colleagues would benefit from having the opportunity to develop their skills in working with autism. This chapter explores the huge difference that a good understanding of autism can have on the effective treatment of mental health problems in children with autism, as well as the devastating consequences that can arise when this is not in place.

## Communication

Whether CAMHS are assessing what the problem is or delivering an intervention, an ability to communicate properly with a child with autism is vital to providing effective support. It is therefore of great concern that less than half (46%) of parents think CAMHS staff know how to communicate with their child.

**“[The psychologist] introduced himself... but he didn't try to get to know me or find out anything... It just traumatised me so much and made things worse. I mean, when I went in to the meeting I was miserable and depressed. When I came out I was suicidal. I was trying to throw myself out of my windows and hang myself... It took me several years to recover and I didn't ever want anything to do with them.”**

**18-year-old woman describing her experiences as a nine year old**

## Paul

Paul is 14 years old and was diagnosed with Asperger syndrome aged seven. Since then, he has struggled to receive appropriate support from CAMHS and to access services which would support his development into adulthood.

Following his diagnosis, Paul was referred to see a psychiatrist on a six-weekly basis because he was displaying behavioural problems. Paul's parents felt that the psychiatrist had a poor understanding of autism and lacked the skills to help with Paul's problems other than by prescribing medication. Paul and his parents did not want him to take medication, but were told that if they refused it they could no longer receive support from CAMHS.

The medication Paul was prescribed was known as an adult drug and was not traditionally prescribed for children in the UK. However, due to the persistence of the psychiatrist at CAMHS and a lack of any alternative, Paul was eventually given it by his parents. After one day the medication led to a dramatic negative change in his personality and his father decided against letting Paul use it again.

“He was like not my child any more, just for one day. I wouldn't give it again after that.”

*Paul's father*

Paul became depressed and suicidal. He drew a picture of himself being shot and killed by arrows, and another of his own tombstone. He also began to run away from school and to self-harm. However, as his father refused to medicate him for fear of Paul losing his personality and degrading his quality of life, the psychiatrist at CAMHS refused to see him again.

Paul had a brief period with another psychiatrist who had an excellent understanding of autism and was beginning to make progress with him, but unfortunately this psychiatrist was moved to another practice. In their next meeting with CAMHS, in which Paul was present and had cried throughout, Paul's parents were told that he was not depressed because he had a weekend hobby. Since then, Paul has received no support from CAMHS, nor have CAMHS attended any school or family support meetings.

Seven years since first accessing CAMHS, Paul's mental health problems continue to worsen.



Communicating with children with autism requires flexibility, patience and skill. A willingness by professionals to adapt the way they work with the child and personalise the support they provide is crucial – a blanket approach simply will not work. For some children this will mean speaking more slowly and clearly; others will have limited or no verbal communication and may need visual cues to help them to make sense of and communicate their feelings. Professionals may also have to adapt how they explain things so that they are less abstract or hypothetical and instead relate more directly to the specifics of the child’s situation. The child is likely to take longer than other children to gain trust in the professional and to communicate openly.

“Our kids know that [CAMHS] don’t understand what their problems are or how to help them. It’s not like they want them to wave a magic wand or something, just to take it all away - they know they have to do work. They know that it’s going to be hard, but they’re very clever at picking up when people don’t understand them.”

*Parent of a teenage child*

Where the professional is given the time and training to get to know the child and their family, to understand the child’s autism and how they are best able to communicate and to adapt their approach accordingly, the outcomes are greatly improved. But a professional who does not understand autism is unlikely to make these adjustments, leading to a breakdown in communication which makes effective intervention all but impossible.



The Mental Health Act Code of Practice has a specific section on autism, which states that mental health service provision requires “special consideration of how to communicate effectively”. It explains that “whenever possible, the people carrying out assessments should have experience and training in working with people with these disorders. If this is not possible, they should seek assistance from specialists with appropriate expertise...”<sup>26</sup>

“I have had a child come in and completely ignore me for the first session but then... I have a certain level of awareness of why he’s doing that. I didn’t take it personally... With autism, it’s a gradual build-up of a relationship and you can’t force it and you can’t push it.”

*Specialist Occupational Therapist*



“I always have to stay as a translator, because [the psychologist] hasn’t learnt to reduce her language enough. [My son] looks at her and once he even said, ‘What are you saying?’ He doesn’t understand.”

*Parent of a young child*

Some children with autism find it much harder than other children to express their feelings. This often results in them keeping things bottled up or pretending that everything is ok. A professional who hasn’t been trained to understand this may discharge the child, seeing no evident symptoms. Other children with autism, who are able to tell their full story, are often left frustrated by an unhelpful response.

“I’ve listened to [my son] open his heart up and describe to them OCD thoughts and how they come into his mind and how he has to do them. I’ve listened to him do that and he’s opened his heart up so much. I’m thinking there’s hope now, he’s said everything so well. Maybe he’s going to get some help. Then when he doesn’t, I think ‘How many times can I take him to open his heart up and to say what he’s done just to absolutely come away with nothing?’ He knows he’s come away with nothing. He just doesn’t see the point in going anymore and he’s started to tell them that.”

*Parent of a teenage child*

## Misdiagnosis

Professionals who do not have a good understanding of autism can misdiagnose children as a result, leading to inappropriate discharge or unsuitable interventions.

Without a sound working knowledge of autism, some of the behaviours that are common in children with autism can easily be interpreted as mental health problems. Autism-related personal obsessions, rituals and routines can lead to false diagnosis of OCD. Peculiarities and fads about what the child is willing to eat can come across as an eating disorder. Sleeping difficulties or an aversion to human touch can wrongly lead to suspicions of abuse-related trauma.

When a child with autism also has a mental health problem, it is crucial that the right support is provided for the right diagnosis. If a child is wrongly assessed then the wrong support inevitably follows.

**“I gave them the idea because my children are very technologically minded and very good on computers, and I said, ‘Don’t even try to talk to him - text him’. He was looking at me going, ‘It sounds bizarre.’ I’m going, ‘Try it.’ So he sat there the whole session just texting and my son actually texted back, and he’s like, ‘My God I’ve got so much from him’ because it was a way that he was willing to communicate.”**

**Parent of a teenage child**

<sup>26</sup>Code of Practice: Mental Health Act 1983, revised 2008, Department of Health

**“Either it can mean depression or it can mean a young person is getting psychotic, or it could mean a lot of other things, and that’s the bit which needs to be unpicked. The sooner it’s done, the better the chance that kid has to have a good quality of life.”**

#### **CAMHS Clinical Lead for ASD**

Some of the children involved in our research who had previously been diagnosed with autism were wrongly ‘undiagnosed’ by a professional convinced that their behaviour was symptomatic of a different condition.

“I was a bit confused already, they made it all a bit worse ... they basically said to me I didn’t have Asperger’s. It really confused me. They said because I made good eye contact and... I didn’t have lots of social problems, that I didn’t have it.”

*13-year-old girl*

Other children’s mental health conditions were ‘over-shadowed’ by professionals who were unable to distinguish the symptoms of mental health problems from autism-related behaviours – if autism was the factor the CAMHS team focussed on, mental health issues were ignored. Some parents told us that the professionals they met saw conditions such as anxiety disorders to be inevitable and unavoidable side-effects of having autism, rather than as a separate, treatable condition.

Having fought to get their children seen by CAMHS, some of the parents we interviewed found themselves being blamed for their child’s behaviours and problems. The finger was pointed at parents for a lack of attachment with the child and poor parenting skills or else they were blamed for ‘molly-coddling’ their children. Yet professionals with a better understanding of autism recognised the importance of working with parents in successfully treating the child’s mental health problems.

“The psychiatrist actually took her diagnosis [of autism] away and changed it to an attachment disorder, which was very worrying. She told me I should have nurtured her when she was a baby.”

*Parent of a teenage child*

“Parents are always the experts and they can read [their children] and read them well.”

*Specialist Occupational Therapist*

## **Making simple adjustments**

The Equality Act 2010, and the Disability Discrimination Act preceding it, make it a legal requirement for reasonable adjustments to be made to the service provided to people with disabilities, including autism. But through talking to parents and professionals, we found that when CAMHS didn’t have good basic training in autism, they were often unable to make these adjustments.



For instance, children with autism can experience high levels of anxiety and stress in new, unfamiliar environments. Some of the children we spoke to found it impossible to relax enough to open up in the clinical settings of CAMHS.

“You need something colourful and happy. You’re supposed to be making people happy, aren’t you?... It’s scary going to a hospital.”

*16-year-old young person*

Others found that professionals understood these difficulties, and were happy to see the children in a setting that worked for them, such as their home or their school.

“We’ll make a decision as to where they work best [home, school or at CAMHS], where they’re most relaxed and comfortable and where there isn’t too much external distraction... I usually give the child the option just to see what they want.”

*Specialist Occupational Therapist*

Children with autism and mental health problems are likely to take longer to treat than children with autism. Professionals report that they need to be flexible with the duration and frequency of their sessions with children with autism for them to work well. They told us that it generally takes longer for them to build trust in the child, and sometimes the autism simply makes the process of assessment and treatment that much longer and more complex.

“Going at their pace is really important, sometimes recognising that you’ll need to see them very frequently... They might not manage an hour - it might be weekly 30-minute sessions... Things like that would be important... dropping it down to a pace that they can cope with.”

*Clinical Psychologist*

## **Training and development**

“I haven’t got [any training] formalised specifically to autistic spectrum disorder, but then I’ve got a few other areas I need to work on as well. So, you know.”

*Community Nurse for children with learning disabilities*

The whole range of CAMHS professionals can come into contact with children with autism, and therefore anyone can have an impact on the support that the child receives through a good, or bad, understanding of autism.

Many of the professionals we spoke to felt strongly that there are not enough training and development opportunities for them to develop their clinical expertise in working with children with autism and mental health problems. The high numbers of children with autism in the CAMHS system, coupled with the lack of skilled professionals, leads to many children either being seen by professionals who are unable to meet their needs, or simply being turned away.

**“These children are not quickly in and out of services. They’re not the six appointments and discharge kind.”**

**Clinical director**

## Joseph

Joseph is a very bright, articulate and creative eight-year-old boy with a great sense of humour. He was diagnosed with Asperger syndrome at the age of three, and has subsequently been diagnosed with co-occurring bipolar disorder, pathological demand avoidance and generalised anxiety disorder.

Joseph particularly enjoys dancing, playing the piano, horse riding and books. He has a loving and caring nature towards other people, animals and the natural environment. His ambition is to become a primatologist.

When his paediatrician became concerned that Joseph may also have mental health problems, he was referred to a local CAMHS. Joseph's parents, who had undertaken a number of training courses with The National Autistic Society, also recognised that Joseph had significant symptoms in addition to his Asperger characteristics. But during the CAMHS appointment, it became clear to Joseph's parents that the professionals had a lack of understanding of Asperger syndrome and believed mental health problems were just a part of Joseph's diagnosis rather than a separate mental health issue. They told Joseph's parents that they were worrying too much.

As Joseph became increasingly unwell, his paediatrician made another referral to a different CAMHS in the area. This referral was rejected on the grounds that the CAMHS did not feel that they had the experience to diagnose or treat serious mental health conditions in a child with Asperger syndrome.

By this time Joseph had become extremely unwell and the paediatrician referred him directly to a consultant and his specialist team at a London hospital, 250 miles away from where Joseph and his family live. Here, Joseph was diagnosed with bipolar disorder, pathological demand avoidance and generalised anxiety disorder, in addition to Asperger syndrome. Joseph continues to be assessed and treated at this hospital and he and his parents have to regularly undertake the 500-mile round trip to attend hospital appointments.

Joseph and his family still receive no support from local services. Between hospital appointments his parents have to rely on remote telephone support from the specialist team in London. A further two referrals to local CAMHS have recently been rejected. Joseph's parents were informed that the reasons for this were that one of the CAMHS was "in a crisis situation" and the other could not help as their family "do not live in the right catchment area for support from that service".

All this points to a real and urgent need. There is clear evidence that a good understanding of autism is vital in order to deliver an effective service to the high number of children with autism in the CAMHS system. All professionals working within CAMHS must have their training needs relating to autism recognised and addressed.

**"I would say it's very patchy, but by and large, people don't feel comfortable at all [working with children and young people with autism]."**

**Clinical Psychologist**

In 'Fulfilling and rewarding lives', the Government's recently published strategy for adults with autism, there is a commitment for "all NHS practitioners [to] be able to identify potential signs of autism, so they can refer for clinical diagnosis if necessary, but more importantly so they can understand how to adapt their behaviour, and particularly their communication, when a patient has been diagnosed with autism or displays these signs"<sup>27</sup> The same strategy commits the Government to working with the General Medical Council and various professional bodies "to improve the quality of autism awareness training in their curricula".

The Government must ensure that these commitments are met by giving CAMHS practitioners the support and training they need.

### Case study: Halesowen apprenticeship training

**Dudley Primary Care Trust operates an autism clinic which focuses on diagnosis and assessment, and has the specialist expertise to assess complex autism cases.**

**The clinic takes a 'broad apprenticeship approach' to training new staff, which gives them the opportunity to observe specialists and more experienced clinicians assessing children from behind a one-way mirror. After the new staff have watched several assessments, they progress to shadowing colleagues and then taking the lead with children with autism, with support from a specialist. Finally, they are able to work alone and train new starters themselves. They learn through practical experience, rather than theory.**

*"We felt that it is really important for all staff to have a good grounding in autism as it is so complex when it co-occurs with mental health problems. It can easily be wrongly diagnosed or labelled, and ultimately those with more complex needs can end up with the wrong label and the wrong treatment. A wrong label has implications, not just for the support we give them, but in education and all aspects of their life, so it is so important that we are able to get that right."*

*Clinical Lead for autism clinic*

**The clinic also shares its expertise more widely, training external agencies. For instance, they trained a group of specialist autism teachers and key workers to provide social skills training to children. This meant that social skills training could continue once the child had left the CAMHS, making it far more effective than if it had been delivered once and then discontinued.**

## We recommend

**that all staff working within CAMHS tiers 2, 3 and 4 must have basic training in autism, and have access to specialist advice.**





## Involving parents and schools

We heard from many CAMHS professionals how importantly they view parental involvement when treating mental health problems in children with autism. They regard listening to the views of parents as a crucial part of the assessment process, as well as seeing great value in involving parents in some therapy sessions. Some professionals even ask parents to work with their children at home between sessions, and equip them to do so.

“We would never work with a child in isolation. Although we might work with one child in a room and without the parents, we would always feed back to the parents afterwards. It is rare that we work with the child on their own.”

*Clinical Psychologist*

But parents told us how often they have been frozen out of the process, unaware of how the professional was working with their child, and given no advice or support about what they could do to support their child at home. In some cases, parents told us that children as young as 13 had been given medical prescriptions without any involvement from their parents, who felt that this was very inappropriate due to the nature of their child's condition. One fifth (21%) of parents do not know what treatments their child is receiving.

Aside from home, children spend most of their time at school. But only one in five parents (21%) believe that CAMHS work well together with their child's school. Parents also told us instances of CAMHS staff failing to attend important school meetings to discuss their child's development.

**“You need to bring the parents on board. They're your greatest allies, the parents. If you've got parents on board for any of the therapies, then you start to win the battle.”**

**Parent of a teenage child**

“I'm forever trying to say [to the school] ‘CAMHS have said this’. For me to remember it all and get it across in the right way, I can't do it as well. Can't they just tell them themselves?”

*Parent of a teenage child*

Mental health problems will often develop in part through the child's experience in the education system. Many professionals told us that it was very important to strike up a good relationship with the child's school - and those who have done so are now able to work with the school to deliver interventions for the child.

**“Part of our service works almost exclusively within the school. So when we pop up we're not seen as alien, we're just seen as another person that works with behaviour support.”**

**Clinical Team Manager**

# More autism specialism needed in the system

- Parents who say that their child has received support from a professional who specialises in autism are twice as likely to:
  - agree that CAMHS has improved their child's mental health
  - be satisfied with the support they received from CAMHS
  - agree that CAMHS knew how to communicate with their child.
- Only 2 out of 5 (43%) parents say that their child has received support from a professional who specialises in autism.

**We have seen how a broad knowledge of autism among all CAMHS staff is essential to ensuring that appropriate interventions are delivered to children with autism. But this alone is not enough.**

Providing mental health support to a child with autism is a specialist skill and our research has found that when an autism specialist has been involved in the support of a child, the outcomes and service satisfaction both improve dramatically. Our survey found that parents who reported that their child has had support from a professional who specialises in autism are twice as likely to agree that CAMHS has improved their child's mental health than those whose children have not. They are also twice as likely to be satisfied with CAMHS. However, only two in five parents say that their child has had this support.

This chapter explores the vital difference that autism-specialist intervention can make to the effectiveness of mental health services, both from the perspective of the parents and children who use the services, and the professionals who deliver them.

## What do we mean by an 'autism specialist'?

Autism specialists can be a variety of professionals. Within CAMHS they will often be psychiatrists or psychologists. We define 'autism specialist' based on the skill set that the professional has, rather than in terms of professional qualifications or job titles.

A specialist will have an excellent, in-depth working understanding of autism and would be expected to be able to:

- recognise and diagnose autism in children, or be involved in a multi-disciplinary autism diagnosis
- communicate effectively with children with autism across the spectrum
- adapt the way that they deliver mental health interventions to meet the needs of children with autism
- support fellow professionals to provide an appropriate service to children with autism through training and advice.

**"Speech and language therapists, occupational therapists, paediatricians, child psychiatrists, psychologists, social workers as well, specialist teachers who have expertise in autism – that would be the team I dream of."**

**Clinical Director**

## Laura

Laura is 16 years old and has Asperger syndrome along with catatonia-like deterioration<sup>28</sup>. She is a sociable, intelligent young person with a very generous spirit.

She is particularly good at science and would love to become either a pharmacist technician or make her own scented products. She is also very keen on drama and wants to become an actress.

"Laura has been extremely brave in challenging the enormous difficulties she has faced. We are so very proud of her."

Laura's mother

Laura began exhibiting obsessive behaviour just before her ninth birthday. Her mood and concentration began to deteriorate and she had trouble sleeping, so she was referred to CAMHS. Six months after Laura's referral, her catatonic-type behaviour and anxiety levels began to increase.

Laura's psychiatrist had lots of experience in working with children with autism and an excellent working knowledge of the condition. The wide range of support and interventions that he was able to offer was excellent and led to real improvement in Laura's mental health. He would often visit her at home when she was unable to leave her house and often sat in on meetings at her school to help facilitate the school's management of Laura's behaviour. Laura's parents were also given a telephone number to call in case Laura entered a catatonic state during holiday periods.

When Laura was 14 years old her mainstream school placement became unbearable for her. Her parents had a very difficult time trying to find a suitable school which could meet her educational needs and take account of her serious mental health issues, but eventually they secured an appropriate placement.

"We would never have secured this placement had it not been for the support and intervention of Laura's Psychiatrist."

Laura's mother





**“I don’t think [the staff who are not autism specialists] have the right training [to work effectively with children with autism]. They’re well trained for generic mental health disorder but not for mental disorder in children with autism.”**

**Clinical Director**

CAMHS would be better placed to provide an autism specialist service if these competencies were officially defined by the Government or professional bodies such as the Royal Colleges. The National Autistic Society would welcome any opportunity to help develop such a competency set.

## The importance of autism specialist intervention

The professionals we spoke to stressed the importance of specialist autism expertise when dealing with a child with autism and mental health problems. They explained how in many cases it requires a very specific skill-set to treat these children, and that without that specialist level of knowledge it can be very difficult to affect any real improvement.

They felt that specialist expertise was often required to get a real understanding of how the child’s mental health problems related to their autism, and how they would need to adapt the interventions they provided to take account of the child’s autism. We learned that while a basic autism knowledge would help a professional to communicate better with the child and have a better understanding of why the child was displaying certain behaviours or symptoms, a greater level of expertise was often needed to make a positive difference to the child’s mental health.

“I think everybody having just a slight awareness would only be a positive thing but in terms of the actual work, having a specialist team does work well.”

*Specialist Occupational Therapist*

The views of professionals were strongly reinforced by what parents told us. Our survey asked parents whether or not their child had received support from a CAMHS professional who specialises in autism in the last three years. The vast majority of the subsequent questions we asked about the quality and effectiveness of the service results were significantly better for those who had answered ‘yes’ to this question.

These parents are, for instance, twice as likely to agree that CAMHS have improved their child’s mental health (42% compared to 19%), twice as likely to be satisfied with the support their child has received from CAMHS (50% compared to 24%), and four times as likely to say that a good understanding of autism from mental health professionals has positively influenced their child’s mental health (41% compared to 11%).

Clearly, when parents reported that their child had been seen by someone they considered to be an autism specialist, they also reported a dramatically improved experience of the service and the perceived outcomes for their child. So why is specialist autism support so important?

## Interventions need adapting

Many therapies and interventions rely on thought processes and communication techniques that do not make sense to children with autism, and only skilful adaptation can make them relevant and useful.

Cognitive behavioural therapy (CBT), for instance, is often used to treat anxiety disorders, depression, phobias and OCD, all of which are common in children with autism. The therapy is designed to change the way that a person thinks and acts by talking through real or imaginary situations and then thinking about how those situations would make them feel, or how they might respond. CBT helps people to see how their own thoughts and actions, rather than the situations they find themselves in, are the source of their problems.

However, when this technique is applied in the normal way to children with autism it can be ineffective. Most children with autism find it extremely difficult, if not impossible, to use their imaginations in the way that CBT requires. They struggle to understand how others feel or to recognise the appropriateness of their thoughts and actions. So, for instance, it may not make sense to a child with autism if you ask them how their teacher feels when they misbehave in class.

An independent study found that people with autism “often suffer from a reduced ability to recognize thoughts and feelings both in themselves and others. This would seem likely to obstruct the introspection often required by CBT. Additionally, language and social skills deficits associated with [autism] could impede the formation of therapeutic relationships and the combination of complex and/or abstract concepts”<sup>29</sup>

But with specialist knowledge of how CBT can be adapted to take account of autism, the therapy can be applied successfully. Adaptations might include increasing the use of visual aides, increasing the emphasis on practical coping strategies, and reducing the use of abstract language.<sup>30</sup>

“They seem to want to treat things separately, she’s got Asperger’s, OCD, and depression, and they get some treatments. We tried CBT for the OCD, it didn’t work, it was counterproductive.”

*Parent of a teenage child*

**“After seeing what my daughters have been through I’m not letting anyone but a specialist near my son, because it doesn’t work with them.”**

**Parent of two teenage children**



<sup>29</sup>R. Lang et al (2009) Treatment of anxiety in autism spectrum disorders using cognitive behaviour therapy: a systemic review, Development Neurorehabilitation 13, 53-63

<sup>30</sup>R. Lang et al (2009), Op cit

There was a feeling among many parents and professionals that, although most CAMHS have a great desire to help and some have a basic understanding of autism, specialist input is often needed when working with children with autism. They explained how non-specialists had been at a loss when their usual techniques did not seem to have any impact, while specialists were able to come up with various different approaches, adapting these to suit the individual child during the course of the intervention.

“I think we’re okay to be honest, at being open, reflective, assessing, listening, carefully thinking about issues, thinking about autism. Up to that point I think we’re not a bad service, but I think once we say, ‘Oh yes, he’s got autism’ then I think we actually don’t really offer very much.”

“It’s about having an expertise, a skill, a knowledge that actually resolves a problem. Some people can think, ‘It’s great coming here and it’s nice talking to people, but it actually doesn’t make things any different.’”

*Clinical Team Managers*



## Specialists build knowledge and awareness among other staff

Autism specialists can help other professionals to develop their own skills base. The autism specialists that we spoke to had used their own expertise to train other professionals at their service, as well as to improve understanding among other local agencies such as schools and social services.

**“She’s like the autism whisperer, I swear. It is possible to come up with strategy after strategy. It’s endless. This woman is amazing.”**

**Parent of young child talking about a CAMHS professional**

## Case study: West Berkshire Social Communication Team

“...the key is a really good assessment, which is based on a thorough understanding of autism and a thorough understanding of the child, then you do a formulation that works for that child rather than trying to apply a blanket that you’ve read works for this disorder...”

West Berkshire has a Social Communication (SoCom) team which provides home and community-based assessment and intervention for young people with complex diagnostic issues or needs that cannot be met by local services. The service sees young people up to the age of 18, whatever their level of ability. The SoCom team also offers a monthly consultation service for professionals working with children and young people who have social communication difficulties.

As part of their service, the SoCom team works with children with autism and a secondary mental health disorder. They are also part of the diagnostic pathway for children with autism.

The SoCom team takes a multidisciplinary approach, incorporating Speech and Language Therapists and two clinical psychologists. They would like to have a psychiatrist as well but this has not as yet been possible. The team is also part of a wider multidisciplinary group who provide services for individuals with autism in West Berkshire. They meet on a monthly basis and look at referrals to stop children with autism falling through the gaps between different teams.

The team recognises the need to adapt therapies to account for autism. Psychologists divide their time between diagnosis and follow-up appointments and also provide behavioural and mental health interventions. Following these, the therapist applies an intervention that works specifically for that child rather than trying to apply a ‘blanket’ rule.

“We work with other agencies in trying to adapt what [they do]... For example, [a school] had difficulty with a child moving from one class to another because he was given a written timetable. He couldn’t understand. He didn’t know what to do. We talked to the school and said it’s better to use cards ... or a map even. Sometimes children [with autism] are very good with maps and visual things. So, when we did that, the problem was solved.”

*Consultant Child and Adolescent Psychologist*

## We recommend

**that specialist autism capacity is made available within all tiers 2, 3 and 4 CAMHS.**



## Research and innovation

Conventional strategies needn't be the only answer to improving the mental health of children with autism. Sometimes an innovative, unconventional approach has made the crucial difference.

One parent told us that for their sons with autism, one of whom had co-occurring depression and self-harming behaviours and the other of whom had an eating disorder, things only started to improve for them when they joined a local football club with one-to-one support. Going to this club significantly improved the way that they related to other people through a constant emphasis on teamwork. It improved their behavioural difficulties and boosted their self-esteem through having fun and making friends.

These children also used CAMHS, but their parents felt that the confidence and social stimulus provided by the football club was a bigger driver in improving their mental health. Another parent told of a similarly positive experience where their son attended a snooker club.

We believe that there must be more innovative solutions out there, just like these. While CAMHS should continue to be the focal point of support for children with mental health problems, these traditional services should not be seen as the whole answer, and we should enable local people and services to find ways to improve mental health that work for them.

There is also a need for more research into the effectiveness of conventional mental health interventions for children with autism. Autism specialists working in CAMHS already have a good idea of what doesn't work when treating mental health problems in children with autism. Many have also developed some excellent practice in treating these problems and regularly see successful outcomes from their interventions.

What we do not have, however, is a clinically recognised, evidence-based understanding of what does and does not work for this group, because very little robust research currently exists.

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Most professionals, including the autism specialists we spoke to, told us that they wanted to see more research into effective interventions as well as national guidance on best practice in treating mental health problems in children with autism.

The National Institute for Health and Clinical Excellence (NICE) is currently considering new clinical guidelines on 'the management of autism spectrum disorders in children'. This would represent an excellent opportunity for mental health interventions and prevention strategies for children with autism to be comprehensively investigated from a clinical perspective.



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## We recommend

**that NICE issues clinical guidelines on providing effective interventions for children with autism and mental health problems.**

**that the Government commissions research into effective interventions for mental health problems in children with autism, and disseminates good practice guidance.**

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**"I think the problem is that we don't actually know what to do with autism and mental health problems. We know, for instance, that CBT can be effective and we know we've got to adapt it, but nobody really knows quite how to adapt it yet."**

**Clinical Psychologist**

# Planning the right services

- 65% of CAMHS support children with autism, but only 10% provide targeted support to this group<sup>31</sup>.
- Just 20% of local Joint Strategic Needs Assessments mention autism.

## Local service planning

Local commissioners have a duty to understand the care and support needs of their local population and to commission services to meet those needs. But the professionals and parents we surveyed are in agreement that, presently, the right services are not being commissioned for children with autism and mental health problems. Something needs to change.

The problems lie firstly in making sure that the right data is collected and secondly in how that data is interpreted by those who make decisions about what services are needed: we need commissioners to know how many children with autism live in their area, and how many of these children also have a mental health problem. The commissioners must then use this data to plan the right services for these children.

There are various planning tools used by commissioners to make sure they are doing this correctly. Joint Strategic Needs Assessments (JSNAs) are used by commissioners to study the local population and plan services to meet their needs. However, a recent study showed that only 20% of JSNAs even mention autism<sup>32</sup>, let alone autism and co-occurring mental health problems.

Another important planning tool is the Children and Young People's Plan (CYPP). The CYPP is the plan in which Children's Trusts set out how they will meet the needs of local children, including identifying how they "will ensure the delivery of the full range of services to support children's emotional wellbeing and mental health across the full spectrum of need"<sup>33</sup>. A recent change in the law now requires these plans to account for children with disabilities. This should include children with autism, and the government guidance also recommends that data should be improved to identify the needs of the most vulnerable groups of children. But the law does not require data about whether children have more than one disability or need, so when autism occurs with a mental health problem this is not necessarily picked up in the plan.

Our survey of clinical directors found that half (51%) do not keep a record of the number of children with autism who use the service. So without the right data being collected, it is no great surprise that the right support is not being put in place.

## We recommend

**that the relevant health and local authority strategic planning tools record data that includes the full range of needs for children with autism, including their mental health problems.**

<sup>31</sup>Wistow and Barnes (2009). Op cit

<sup>32</sup>Clark et al. (2009) Supporting people with autism through adulthood, The National Audit Office

<sup>33</sup>P 75, Statutory guidance on co-operation arrangements, including the Children's Trust Board and the Children and Young People's Plan (2010), DCSF



**"If you look at the waiting lists and waiting times, the autism and the ADHD ones are similar. They are very long times, and they are a very high proportion of referrals into CAMHS. [Waiting times are longer for those groups] because there aren't enough of us doing it, and other people get anxious about doing ADHD as well as doing autism."**

**Clinical Psychologist**

**"Almost the first thing the psychiatrist did was to hold up their hands and say... 'we have no services in this health district for children on the autistic spectrum!'"**

**Parent of a teenage child**

Data should also be collected to measure how well services are working for children with autism. Commissioners should be monitoring waiting lists to see if a disproportionate number of children with autism are waiting to be seen. Some professionals told us that the waiting times for children with autism in their areas were longer than those for other children, simply because they did not have enough professionals who felt comfortable or skilled enough to deal with those children.

Commissioners should also be looking at rates of return for children with autism – are a larger than average number of children with autism returning to CAMHS with recurring problems? If so, would longer interventions in the first place prevent these higher rates of return?

Some CAMHS also monitor outcomes for children and families, so that those children and families have the opportunity to say how well the service has been working for them at intervals during treatment and again at discharge. Comparing outcome data between children with autism and other children would again help commissioners to understand how successfully their services are helping children with autism.

*"What I think would be interesting is looking at the averages of those kinds of cases - how long is the work, how many sessions? What's it like, what outcomes are we getting... I'm trying to put that all together. I think that there's a lot that we need to do to evidence ourselves."*

*Principal Clinical Psychologist*

*"We do try very hard to get people's feedback... everybody gets a pre-treatment screen, gets an opportunity to tell us what their concerns are, and then at six months into treatment or at discharge they get a second opportunity to tell us what they think we've done which has added anything to their experience."*

*Clinical Team Manager*

## We recommend

**that health and local authority commissioning must take specific account of CAMHS waiting times, rates of return and family outcomes for children with autism.**

## Peter

Peter, aged 10, was referred to CAMHS three times before he was offered any support. He was diagnosed with autism, ADHD, Oppositional Defiant Disorder and possible Bipolar Disorder. He is non-verbal and self-restricts his diet.

Peter loves trawling charity shops for bargain DVDs and videos, and making people laugh by imitating funny phrases and sayings.

He was referred to CAMHS three times as a result of persistent self-imposed dietary restrictions and self-harming behaviour. After the first two referrals, CAMHS refused him any support. CAMHS only offered intervention after his third referral, following his hospitalisation as a result of these behaviours.

Even at this stage, CAMHS seemed unsure about how they could help Peter, and offered no ongoing strategies or support. He was simply prescribed with a course of Risperdal, with no additional treatments offered or attempted.

During one particularly bad incident Peter hit his head against a wall for three hours, leading to hospitalisation. When he was taken to hospital he was made to wait three hours for someone from CAMHS before he could be discharged, but no one turned up.

When Peter was at the peak of his self-harming behaviour, CAMHS did not provide any support. This lack of help has left Peter's parents feeling isolated, frustrated and worried about their son's safety.

"My greatest fear was that my son was going to die because he was starving himself to death."

Peter's mother



## Increasing understanding amongst commissioners

Having the right data is only one piece of the puzzle. Making this data translate into services is crucial, and relies on commissioners understanding what support works for children with autism and mental health problems and what does not.

The professionals that we spoke to felt that commissioners did not have a good understanding of what children with autism and mental health problems need; in particular the need for local training strategies to address gaps in autism knowledge across all frontline professionals and for sufficient autism-specific support to be available within CAMHS. It's important that commissioners also recognise that children with autism will, in most cases, take longer to treat. To inform commissioners on these issues, we need:

- 'Experts' to be involved in the commissioning process  
Commissioners should be talking to parents and children affected by these issues, as well as to professionals, to gain a real understanding of where things aren't working and where new services are needed.
- Government guidance  
Commissioners will respond to direction from the top about the needs of children with autism and mental health problems and what services should be provided to meet their needs.

"The commissioners, the local authorities and the Primary Care Trusts (PCTs), they're all sitting in a room saying, 'CAMHS should do this,' but how do they know what we should be doing? How do they know what we can do? They're not checking out with us whether that's possible ... and they're not physicians. So, do they know what we really can do? I don't think they can."

*Clinical Director*

In October 2009, the Government produced statutory guidance on 'promoting the health and emotional-wellbeing of looked after children'<sup>34</sup>. This includes specific statutory guidance for commissioners to help them to plan appropriate CAMHS for looked-after children. The guidance includes specific instruction on identifying gaps in provision for this group, developing clear referral pathways, and "providing targeted and dedicated services to looked after children where this is an identified need". Similar guidance is urgently needed to help commissioners plan services for children with autism.

## We recommend

**that all Primary Care Trusts must demonstrate their commitment to involving people affected by autism in planning and delivering local CAMHS.**

**that the Government issues new statutory guidance to commissioners to support the effective planning and commissioning of appropriate local services for children with autism and mental health problems.**

**"About one in ten children I work with [has autism]. They take up nearly 60% of our time."**

**Consultant Child and Adolescent Psychiatrist**

## How Government initiatives have increased provision of learning disability services

The number of CAMHS who provided specialist support for children with a learning disability more than doubled in the two years between 2005 and 2007 (from 33% to 69%)<sup>35</sup>. The latest Government figures published in 2010 state that 67% of PCTs gave themselves the highest score (4 out of 4) when rating their provision of a full range of CAMHS for children with learning disabilities. A further 32% rated themselves as 3 out of 4, with just one PCT submitting a score of 2<sup>36</sup>. This considerable increase can be attributed to the various Government directives that have identified the need to prioritise services for this group.

### *National Service Framework*

In 2004, the National Service Framework (NSF) for Children, Young People and Maternity Services stated: "There is a need to ensure that children and young people with learning disability who require psychiatric care have access to appropriate services that meet their needs and that they are not disadvantaged because of their disability"<sup>37</sup>.

The NSF highlights the importance of providing an adequate CAMHS service for children and young people with a learning disability and a co-occurring mental health problem. Services were expected to include:

- specialist staff training for staff working within tiers 2 to 4
- adequately resourced tiers 2 and 3 learning disability specialist CAMHS
- access to tier 4 services providing inpatient, day patient and outreach units.

### *A 'comprehensive CAMHS'*

The NSF also sets out that specific services for children with a learning disability must be in place for a local area to be delivering a 'comprehensive CAMHS'. This requirement has driven a range of measures to monitor the progress of CAMHS in developing specific learning disability services.

The Government's 'Public Service Agreement' for improving mental health and psychological wellbeing<sup>38</sup> includes a specific indicator which measures "the development and delivery of CAMHS for children and young people with learning disabilities"<sup>39</sup>. This means that local authorities must score themselves on their progress and report to the Department of Health. This is mirrored by a similar requirement in the 'Vital Signs' indicator for Primary Care Trusts (PCTs)<sup>40</sup>.

In addition, the Care Quality Commission, which has responsibility for inspecting CAMHS, specifically inspected CAMHS commissioners on whether they have commissioned "a full range of CAMH services for children and young people with learning disabilities". It has also monitored whether PCTs "have protocols in place to ensure the range of services provided reflect the specific needs related to the circumstances of the child, particularly where associated with the presence of a learning disability"<sup>41</sup>.



## Pathways for referral and care

Waiting for referrals and appointments is considered by the parents we surveyed to have a negative impact on their children's mental health.

Parents are twice as likely to say that CAMHS has improved their child's mental health (38% compared to 21%) and more than twice as likely to be satisfied (46% compared to 19%) with the service if they have waited less than 18 weeks for a first appointment.

**"...ultimately it would be productive if we could establish... a care pathway. We know that at certain stages [there are] certain needs, so I think there is a need to get together and come up with something a bit more joined up."**

### **Clinical Team Manager**

Parents and professionals are equally frustrated by the confusing and often opaque nature of the CAMHS pathways for care and referral. The routes in for children with autism to get support for their mental health problems are not always clear, nor is the process for receiving post-diagnostic support. There is also confusion around who should take responsibility for the care and treatment of the child at the various stages of treatment, how long it is acceptable to wait for support following referral and what follow up should happen after the child has been discharged.

Professionals and parents both feel that clear pathways for referral and care should be developed to make the service pathway transparent for all involved.

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## We recommend

**that each Primary Care Trust develops specific pathways for mental health support for children with autism.**

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<sup>35</sup>Wistow and Barnes (2009)

<sup>36</sup>Vital Signs Monitoring Return, quarterly update, Department of Health, May 2010

<sup>37</sup>Department of Health (2004) Mental health and psychological wellbeing of children and young people. National service framework for children, young people and maternity services. London: Department of Health/Department for Education and Skills. Standard 9 p21

<sup>38</sup>PSA 12: Improve the health and wellbeing of children and young people

<sup>39</sup>National indicator 51

<sup>40</sup>VSBI2: the effectiveness of CAMHS

<sup>41</sup>CQC Annual health check 2005/06 - 2008/09





## Inpatient units (Tier 4)

A higher proportion of the children with autism in the CAMHS system are currently in Tier 4 than any other children (6.5% compared to 4.5%)<sup>42</sup>.

The children who use Tier 4 CAMHS have the most complex or serious mental health needs, and will usually be extremely vulnerable. The majority of Tier 4 services are inpatient units, although some highly specialised outpatient teams are also considered to be Tier 4. Examples include secure forensic adolescent teams, eating disorder teams, specialist psychiatric teams and other specialist teams, such as for children who have been sexually abused.

Children in inpatient tier 4 units are in the constant care of professionals – they do not have their parents around to ‘translate’ or to advocate for them. So it is absolutely imperative that the children who use these services are supported by professionals who understand their autism and other communication and support needs.

Mainstream inpatient units can be inappropriate environments for children with autism, with lots of clutter, people coming and going in every room, TVs left on and so forth. This can cause stress for children with autism who need a low arousal environment. Children in inpatient units may also be expected to join in with ad hoc social activities, such as a minibus trip to the seaside or to a theme park, which can cause real anxiety unless time is taken to prepare the child well in advance. Professionals without autism expertise may not be aware of the need for such adjustments.

Staff in a generic setting may also misinterpret the behaviours of children with autism – for instance, staff considered one child to have conduct issues because he continually took down curtains, pictures and lights. In fact, he was merely responding to the stress caused by the high stimulus environment he had been placed in.

Because of the complexity and vulnerability of children with autism who use Tier 4 CAMHS, any service failures can have a devastating impact on them. A specialist understanding of autism is vitally important.

The NHS National Specialised Commissioning Group (NSCG) outlines activities within the NHS that should be regarded as specialised and should therefore be commissioned at a regional level. The NSCG has identified “neuropsychiatric / neurodevelopmental services for children and adolescents including those with a dual diagnosis” as a tier 4 specialised service<sup>43</sup>. This definition would include services for children with autism and mental health problems, and further demonstrates that specific services are seen as important for this group.

<sup>42</sup>Wistow and Barnes (2009). Op cit

## Tim

Tim was diagnosed with Asperger syndrome aged eight. For the next decade he struggled to receive support from CAMHS for his ADHD and depression. Tim was highly intelligent and wanted to attend a local school and live a normal life. He committed suicide in an inpatient unit at the age of 17.

Tim’s ADHD was undiagnosed until the age of 16. It meant that he found it difficult to concentrate at school, and was a big factor in him being diagnosed with depression aged 10. He was prescribed with various medications over the next three years, and his prescription of Risperidal, at twice the recommended adult rate, led to him becoming psychotic.

At 13, Tim was suicidal. His parents were left to cope without any support from CAMHS. Tim would hang himself if left on his own, so his parents had to supervise him all around the clock. He was eventually admitted to a Tier 4 CAMHS unit, where he encountered girls with anorexia and others who self-harmed. Because of his Asperger syndrome, he began copying this behaviour. By the time his parents withdrew him from the unit he weighed just six stone.

Over the next few years Tim was moved in and out of secure adolescent units, residential educational settings and eventually, against his parents wishes, into a flat of his own, aged 17. Within weeks of moving into the new flat Tim tried to commit suicide, and was again admitted to a secure unit.

Medical staff at the unit were told that Tim would ask for medication when he needed it. They were also warned to remove anything from his room that might facilitate self-harm or hanging, and to take any warning signs of stress seriously because of his Asperger syndrome and his history. Doctors had assessed him as being at an extremely high risk of self-harm and suicide.

One evening Tim asked for medication from a nurse at the unit. This request was refused, even after Tim had been left with a razor and repeatedly cut himself with it. Tim was told that the nurse would come and see him in five minutes. This did not happen and Tim committed suicide after having been left alone with his shoelaces in a room with ligature points.

“They were actually making out that they had cared for him and they understood Asperger's, when clearly they had no idea. I mean, if you tell somebody with Asperger's you are going to go and see them in five minutes, you go and see them in five minutes, because they know exactly when that five minutes is up.”

Tim's mother

“...if we compare ourselves to things like cancer services and heart services, where it's recognised that you need to have the expertise concentrated... I think we need to think like that ourselves to get the best results for our patients [with autism].”

Clinical Director

## Rachel

Rachel is 18 years old and has Asperger syndrome. She tends to partake in copycat behaviour which can put her in dangerous situations. She has received little and often inappropriate support from CAMHS.

Rachel's Asperger syndrome was initially dismissed by professionals as "Middle Child Syndrome" and then as post-traumatic stress following suspected sexual abuse – an entirely false allegation that was later retracted.

CAMHS refused any treatment, telling the family that there was nothing wrong with her. Having been excluded from one school, Rachel started at a new mainstream school. The setting was completely inappropriate for her autism and mental health problems, and the resulting stress led to Rachel taking an overdose. It was after this overdose that CAMHS decided to offer support. She was hospitalised, which is where her copycat behaviour was discovered. Prior to hospitalisation Rachel had never physically harmed herself but she began copying the self-harming behaviours of other patients.

"Then we found out she had copycat behaviour, and people in there, even though it's a secure unit, had lighters, and they were burning themselves. The other kids there were burning themselves so she was burning herself, and then somehow she got a razorblade in there and she just made a mess of herself."

Rachel's mother

Even simple things like watching TV were dangerous for Rachel - she attempted to hang herself after watching similar behaviour in a soap. The hospital decided to send her home with a follow-up appointment to see a consultant, who then diagnosed her with Asperger syndrome. He also recommended against her ever being hospitalised.

Rachel continued to self-harm, was given Risperidal, which caused difficult side-effects, and eventually was admitted into another inpatient unit by CAMHS. It was at this unit that she began to elicit more copycat behaviours, which led to her vomiting by copying a patient with bulimia. The hospital decided to sedate her and release her to the care of her parents. Rachel and her parents received no further support from CAMHS.

Sadly, these are not isolated incidents and are symptomatic of failures in the system. We strongly believe that such tragedies are entirely avoidable if autism specialism at Tier 4 is made more widely available.

## We recommend

**that autism-appropriate tier 4 services must be available at a regional level.**



### Case study: The Hawksmere Centre<sup>44</sup>

The Hawksmere Centre in Hertfordshire is a newly-opened autism-specific tier 4 CAMHS service. It was set up specifically to treat boys aged between 13 and 18 who have autism with co-occurring mental health issues and complex care needs.

The Centre aims to provide a person-centred service, delivering specialist assessment, therapeutic intervention and support in a safe and secure environment. The team includes consultant psychiatrists, child and adolescent psychologists, speech and language therapists, occupational therapists, nurses (paediatric, mental health and learning disability) and an education specialist.

The new therapy team will work with the child and their parents to create a person-centred care plan that meets the needs of the individual. They also aim to provide a rapid and accessible service in times of crisis, as well as a safe environment.

The Centre will offer support with the transition into adult care and appropriate step-down services via the Autistic Spectrum Conditions specific care pathway. Each transition plan is personalised by the Transition Co-ordinator, who uses a variety of tools such as story boards and Social Stories™ to ensure minimum disruption and anxiety to the young person.

The Hawksmere Centre team explained to us why they feel an autism-specific service is crucial at Tier 4:

"Staff can only begin to offer meaningful support to a person with autism if they have an understanding of what the world looks like from an autism perspective. Autism-specific environments can ensure that all staff are fully trained in autism and that every activity is appropriately focussed around the needs of young people with autism. This cannot be achieved effectively in an environment where staff have to switch their approaches from young person to young person, dropping in and out of their trained autism mode."

<sup>43</sup>p78, Specialised Services National Definitions Set (3rd Edition), Specialised Services for Children – Definition No. 23, National Commissioning Group

<sup>44</sup>The Hawksmere Centre was yet to receive its first referral at the time of writing, so this information is based on the Centre's intended service delivery plan.

# Conclusion

**Throughout this report, we have seen that it is essential for professionals to have a good understanding of autism if they are to treat mental health problems in children with autism. We have also seen the enormous difference specialist autism support can have in improving outcomes for this group.**

We have learnt how children with autism and their families have struggled to access the right services, or even any services - often at times of the most urgent need.

In researching this report we have come across some pockets of good practice across the country. Good practice can look very different across the NHS, from one CAMHS to the next, and different approaches work for different services. But what unites the good practice we have found is that it has been driven by individuals who have the personal interest, passion and dedication to take it upon themselves to become autism experts or champions. Very rarely has a good service for children with autism come about through strategic or structural developments within the PCT or the CAMHS.

This inevitably leads to a very patchy service, both within the local area and throughout the country. But children and their families should expect to receive a consistently effective service wherever they live and whichever CAMHS they access. They should expect all staff to have a good understanding of autism and for specialist autism support to always be available. If we aspire to achieve this level of consistency, the change needs to be driven by national Government.

This report has demonstrated how, in the case of learning disability, prioritising support for a specific disability can lead to a real increase in the availability of specific services. As a result of several Government initiatives, the availability of specialist support for children with a learning disability has increased considerably.

The number of children with autism accessing CAMHS is equal – slightly higher even – than the number of children with a learning disability, yet there is an alarming lack of specialist autism provision. And just as children with a learning disability need support which takes account of their particular disability, children with autism need to have their own disability recognised too.

There is still a very long way to go to improve CAMHS for children with a learning disability, and it is absolutely right for services for children with a learning disability to continue to be a target for improvement. But we believe that there is an overwhelming evidence base for a similar priority to be given to services for children with autism. This situation requires urgent action from the Government.

## We recommend

**that the Government must specify autism as a target area for reform of CAMHS.**



## Summary of recommendations

### A greater Government focus

**We recommend** that the Government must specify autism as a target area for reform of CAMHS.

**We recommend** that the Government commissions research into effective interventions for mental health problems in children with autism, and disseminates good practice guidance.

**We recommend** that NICE issues clinical guidelines on providing effective interventions for children with autism and mental health problems.

**We recommend** that the Government amends its definition of emergency CAMHS provision to better meet the needs of children and families.

**We recommend** that the forthcoming statutory guidance on services for adults with autism must include duties around transition in mental health services.

### Building autism capacity in CAMHS

**We recommend** that all staff working within CAMHS tiers 2, 3 and 4 must have basic training in autism, and have access to specialist advice.

**We recommend** that specialist autism capacity is made available within all tiers 2, 3 and 4 CAMHS.

**We recommend** that autism-appropriate tier 4 services must be available at a regional level.

### Improving local planning and commissioning

**We recommend** that the Government issues new statutory guidance to commissioners to support the effective planning and commissioning of appropriate local services for children with autism and mental health problems.

**We recommend** that the relevant health and local authority strategic planning tools record data that includes the full range of needs for children with autism, including their mental health problems.

**We recommend** that health and local authority commissioning must take specific account of CAMHS waiting times, rates of return and family outcomes for children with autism.

**We recommend** that all Primary Care Trusts must demonstrate their commitment to involving people affected by autism in planning and delivering local CAMHS.

**We recommend** that each Primary Care Trust develops specific pathways for mental health support for children with autism.

**We recommend** that commissioners ensure that local CAMHS have the capacity to provide 24-hour support to children and families who need it.

# Research methodology

## The research for *You Need To Know* involved four main stages of work, as described below.

### A. Qualitative discussions with children and young people with autism who have experienced mental health issues, and their parents.

In August 2009, children and young people with autism and mental health issues were invited, along with their parents, to explore their perceptions of the service they received from CAMHS. Participants were recruited through a variety of ways: we contacted people who had responded to a previous survey about child mental health in 2007 and also publicised the research through The National Autistic Society's website, regional teams and branches.

The table below shows the numbers of participants in the discussion groups and one-on-one interviews in London and Leeds.

Age group	Discussion groups with parents/carers	Number of parents/carers per discussion group	One-on-one interview with parents/carers	One on one interviews with children/young people
10 years and under	1	6	0	3
11 to 15 years	1	7	0	8
16 to 18 years	1	9	1	3
<b>TOTAL</b>	<b>3</b>	<b>22</b>	<b>1</b>	<b>14</b>

The sample represented groups of children and young people across the autism spectrum, from those with autism and learning disabilities to those with high-functioning autism or Asperger syndrome. The children had experienced one or more mental health issues, for example: anxiety, depression, ADHD, OCD, post-traumatic stress disorder, psychosis, self-harm, suicidal thoughts and attempted suicide.

### B. Quantitative survey of CAMHS Clinical Directors in England.

The National Autistic Society designed a quantitative questionnaire to gather data from Clinical Directors of CAMHS in England to better understand structures as well as the services available to children and young people with autism, including Asperger syndrome.

The survey was sent out by post accompanied by a covering letter explaining the purpose of the research and giving reassurances about the confidentiality of their responses. There was no incentive for respondents to complete the survey.

Responses were entered into a survey analysis software package and analysed on an anonymous basis to produce aggregated tabulated results. Responses to open-ended questions were also coded for analysis.

Surveys were sent to 69 Clinical Directors in England and we received 47 responses between July and August 2009. This is nearly universal coverage of all mental health provider trusts in England, of which there were 73 at the most recent count. The confidence interval of this sample size, at the 95% level, is + 8.2 percentage points.

### C. Quantitative survey of parents of children and adolescents with autism who may have experienced mental health issues.

The National Autistic Society designed a quantitative questionnaire to find out more about the experiences of children and young people<sup>45</sup> with autism, including Asperger syndrome, of mental health services, via their parents and carers<sup>46</sup>. The questionnaire covered experience of mental health issues, access to and interaction with mental health services, treatments received, impact on and support for the wider family and transition into adult mental health services.

A total of 8,104 people were invited to complete the survey online in two different ways:

- a link to the survey was included in the January 2010 e-newsletter to NAS members in England – this was sent to 8,020 people<sup>47</sup>
- 84 other parents and carers who had either been involved in the qualitative stage of the research or had expressed interest in the research but were unable to attend the discussion groups were invited to complete the survey.

There was no incentive for respondents to complete the survey. The introduction to the survey explained the purpose of the research and gave reassurances about the confidentiality of the responses. Responses were entered into a survey analysis software package and analysed on an anonymous basis to produce aggregated tabulated results. Responses to open-ended questions were also coded for analysis.



<sup>45</sup>We asked parents to respond if they had a child with autism aged 0-21

<sup>46</sup>People with autism aged 16 to 21 were also invited to complete the survey

<sup>47</sup>Our current membership records do not record whether members are people with autism or parents/carers of someone with autism.



## Sample

A total of 558 responses were received from parents and carers of children and young people with autism, which represents an overall response rate of 7%. After removing 88 ineligible responses, a total of 455 responses from parents and carers were data-processed and analysed.

The confidence interval of this sample size, at the 95% level, is + 4.6 percentage points – so if the percentage is stated as being 50%, the true figure lies somewhere between 45.4% and 54.6%.

The profile of children and young people who their parents and carers were responding about is as follows:

Gender: 14% Female  
73% Male  
13% Not stated

Age<sup>48</sup>: 0-5 years old: 1%  
6 to 10 years old: 17%  
11 to 13 years old: 18%  
14 to 17 years old: 14%  
18 to 21 years old: 8%  
Prefer not to say: 41%

Diagnosis: Asperger syndrome/High-functioning autism: 43%  
Autism Spectrum Disorder/Autism: 26%  
Autism with a learning disability: 12%  
Other: 4%  
Prefer not to say: 15%

### D. Site visits to CAMHS services in England.

Site visit participants were recruited through those who responded to the Clinical Director survey described above. The National Autistic Society sent a letter to Clinical Directors to explain this further stage of research and once again to reassure participants about the confidentiality of their responses.

Thirteen one-on-one discussions were conducted in February 2010 in five CAMHS in the South West, South Central, Yorkshire and Humberside and West Midlands Strategic Health Authorities. Interviews were conducted with mental health professionals such as Clinical Directors, Occupational Therapists, Community Nurses, Clinical Psychologists, Child & Adolescent Psychiatrists and Child & Adolescent Psychologists.

A discussion guide was designed by The National Autistic Society and covered topics such as a service overview, autism-specific experience, interventions and approaches that work well, issues and barriers faced by the service, parental and school involvement and transition.

<sup>48</sup>This adds up to 99% rather than 100% due to rounding.







The National  
Autistic Society

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**The National Autistic Society is the UK's leading charity for people affected by autism.**

Over 500,000 people in the UK have autism. Together with their families they make up over two million people whose lives are touched by autism every single day.

Despite this, autism is still relatively unknown and misunderstood. Which means that many of these two million people get nothing like the level of help, support and understanding they need.

***Together, we are going to change this.***