YOU NEED TO KNOW
THOUSANDS OF CHILDREN WITH AUTISM FACE A FUTURE OF MENTAL HEALTH PROBLEMS. NEEDLESSLY.
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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Written by Shirelle Stewart
All case studies of children with autism in this report are as reported by parents. To protect their identities, no case studies use real names, and all photographs in the report use models.

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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.

• Just over one quarter (29%) of parents of children with autism who we surveyed believe that CAMHS had improved their child’s mental health.

• 9 out of 10 parents who took part in our research told us that the mental health problems faced by their child had had a negative impact on their own mental health (87%) and on the family as a whole (84%).

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. Research carried out in England suggests that more than seven in ten children with autism also have a co-occurring mental health problem. Many of these problems are preventable, with the right support. Our research into children with autism and mental health problems indicates that more needs to be done to stop these problems from occurring, and better support needs to be available when they do occur.

Unfortunately, once these mental health problems develop, children with autism aren’t always getting the necessary support from child and adolescent mental health services (CAMHS) which are intended 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.

This report provides a snapshot of the mental health problems that children with autism in Northern Ireland are experiencing. It does not claim to be a comprehensive analysis of the situation in Northern Ireland. Rather, it reflects the experiences of parents who took part in our survey and seeks to make their voices heard. In doing so, it highlights the difficulties families face in getting the right support and draws attention to the profound impact that a child’s mental health problems can have on the whole family.

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, understanding and predicting other people’s feelings and managing their own; understanding verbal and non-verbal language; understanding and predicting other people’s intentions and behaviour; and imagining situations outside of their own routine.

Mental health

Many 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. These can also affect children with autism.

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 all 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 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 or through coping mechanisms such as self-harm.

ASD is not a mental health issue, although ignorance of its demands can result in causing mental health issues.

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

There is no Northern Ireland-specific research into the prevalence of mental health problems in children with autism. However, research in England has demonstrated that nearly three-quarters of children with autism develop mental health problems like depression, anxiety disorders, ADHD and OCD (see figure 1). This compares to a prevalence rate of around 10% in other children in Great Britain. It is estimated that mental health problems in children in Northern Ireland are much higher than in the rest of the UK, due to living with the Troubles and higher levels of socio-economic deprivation. The Royal College of Psychiatrists’ Council report Building and sustaining specialist child and adolescent mental health services, estimated that more than a fifth of young people in Northern Ireland are suffering significant mental health problems by their eighteenth birthday.

In our own survey of over 100 parents of children with autism in Northern Ireland, all of the respondents told us that their child had experienced mental health problems. These included a range of conditions such as anxiety, depression, OCD, self-harm and suicidal thoughts. This was reiterated by the health professionals we interviewed as part of our research, who reported seeing ADHD, clinical depression, anxiety disorders and OCD occurring in children with autism at their CAMHS. Conduct disorder, oppositional defiant disorder, eating disorders and psychosis were also cited.

Our research

The National Autistic Society Northern Ireland carried out quantitative and qualitative research involving 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 those of their families and carers, and face-to-face interviews with professionals in health and social care trusts.

Of the children we received responses about, the majority (88%) were male. The most common diagnosis was Asperger syndrome (47%), with autism spectrum disorder (ASD)/autism (21%) and autism with a learning disability (13%) also common. The most commonly reported mental health issues that the children had experienced were anxiety (76%), behavioural issues (including defiance and non-compliance) (59%), depression (24%), ADHD (21%)/ADD (16%), suicidal thoughts (20%), self-harm/injury (20%), OCD (19%), eating disorders (18%), and conduct disorder (12%).

The parents we surveyed reported that their children’s mental health problems were developing at very young ages. Almost nine out of ten told us that their children first experienced these issues before the age of ten, and over half before the age of five, as illustrated in figure 2.

When we asked parents about what things negatively affected their children’s mental health, the most common answers related to:

• not getting the right support for their child’s autism (58%)
• lack of social support (55%)
• non-mental health professionals, including GPs, social workers and schools, not having enough understanding of autism (48%)
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Services for people with autism have historically been underfunded in Northern Ireland, and until recently parents in some areas have waited between three and five years to get an autism diagnosis for their child. Thanks to recent work by the Regional Autistic Spectrum Disorder Network (RASDN), these waiting times have been substantially reduced. However, intervention services are still underdeveloped.

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. 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. An inability to express their own feelings can lead to escalating emotions or being unable to deal with experiences such as loss or grief.

**How experiences at school can affect mental health**

As our survey has shown, education plays an extremely important role in the mental health of children with autism. Difficulties at school and elsewhere may affect children's self-esteem. A supportive educational setting which works in partnership with mental health services can be crucial in maintaining emotional wellbeing and preventing mental health problems from developing or escalating. Research in England highlighted the link between a delay in accessing the right support at school and poor mental health.

“There was lots of confusion at school for him. He ran out of the school and was quite disruptive – although he is not a disruptive child, his behaviour was. He was knocking things over on purpose and pulling pictures down because he was very confused and upset inside. He had no support at the time and everything just came to a head, and it probably did contribute to his mental health.”

*Parent of a six-year-old*

A number of the health professionals that we interviewed as part of our research emphasised the importance of a good relationship between CAMHS and schools. More awareness and a better understanding of autism among teachers can also make a huge difference. Adjustments within the classroom to assist a child with autism can be easily implemented and can often benefit the whole class.

“The strategies to help someone with autism in school are not difficult to implement and if the school is accommodating, then things move very easily. If there is not the understanding then it can create difficulties. You can set up strategies in school and then, because they lack understanding and the child is not having a problem any more, they take away the strategies and all of a sudden wonder why the child’s having problems again. If there is good co-ordination of service provision across the agencies in terms of health and education then that can work very well.”

*Specialist health professional*

However, there are no mechanisms in place to ensure effective co-operation between CAMHS and schools. Often co-operation is based on the personal relationships between clinicians and schools. CAMHS tend to be overstretched, with intense pressure placed on their staff, so joint working can be difficult for clinicians to achieve.

Plans are being developed to improve provision and help meet the needs of children with autism in the school environment. The Department of Education Northern Ireland is in the process of developing an ASD strategy, which should be published later this year.

**We recommend**

more training for education professionals, such as teachers and classroom assistants, to enable them to implement strategies and create an ethos of understanding which will benefit children with autism

that the ASD strategy being developed by the Department of Education includes protocols to facilitate joint working between CAMHS and schools.
How a lack of public awareness can affect mental health

Awareness and consideration from the general public also has an impact on the mental health of children with autism and their families. 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, which can cause considerable stress and anxiety.

How a child’s mental health can affect the whole family

It is easy to imagine how mental health problems in one child can also have an impact on the rest of the family, especially when the right support is not given.

Nine out of ten parents told us that the mental health problems of their children faced had had a negative impact on their own mental health, with a slightly higher proportion saying that it had led to a negative effect on the mental health of the family as a whole.

Three quarters of parents who say there has been a negative impact on the family said that they see less of their friends and wider family, with the same proportion saying that they no longer go out as much as a family or at all. The majority of parents reporting a negative impact on their family said that they have less time for their other children and that the relationship between them and their partner had been negatively affected. Mental health problems can also have a financial impact, with a significant proportion of parents having to reduce their working hours.

“Our whole family is suffering. I have had to give up work and we don’t have the expertise to deal with these issues. All we want is the right support from professionals who understand our children and for them to be safe, happy and able to cope.”
Parent of a teenager

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 and fulfilling 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.

What is the role of CAMHS in Northern Ireland?

CAMHS were set up to promote the health and psychological wellbeing of children and young people and to offer assessment and treatment as well as give support to families.

In the broader sense, CAMHS refers to all services that have a role in the mental health care of children and young people, like schools, GPs and social services.

CAMHS offer four different types of support for children and their families, referred to as ‘tiers’. England, Scotland, Wales and Northern Ireland have in principle adopted similar approaches to providing services based on the four tiers of support outlined below:

Tier 1
Non-specialist services, rather than specialist mental health services, like GPs, school nurses, teachers, social workers, health visitors, etc.

Tier 2
Mental health specialists working in community and primary care settings, for example psychologists and counsellors in GP practices, paediatric clinics or schools.

Tier 3
Multi-disciplinary teams or services working in a community mental health clinic or child psychiatry outpatient service, providing a dedicated service to children with complex, severe and persistent mental health problems. Team members are likely to include child and adolescent psychiatrists, social workers, clinical psychologists, occupational therapists, and art, music and drama therapists.

Tier 4
Day units and highly-specialised outpatient teams and inpatient units for children with the most serious and complex problems. The Belfast Trust provides Tier 4 services for the whole Northern Ireland region.
What is the structure of CAMHS in Northern Ireland?

All CAMHS in Northern Ireland have now been restructured to ensure that they take children up to the age of 18.

Northern Trust
Provides an integrated, specialist community-based multidisciplinary service operating from three locations.

Belfast and South Eastern Trust
Belfast Trust provides services for those living in both the Belfast and South Eastern Trust areas, with clinics in various locations.

Southern Trust
Provides a specialist mental health service working with children and young people up to the age of 18 and their families. They operate out of three clinics in the Southern Trust area.

Western Trust
Provides a multidisciplinary service and also has two teams, one in the Northern Sector (based in Londonderry) and one in the Southern Sector (based in Omagh).

Beechcroft
This new Tier 4 inpatient service has recently opened for children and adolescents in the Belfast area, providing services for the whole Northern Ireland region. Each trust has an allocated number of beds in this unit, which is provided in the Belfast Health and Social Care Trust area.

Adolescent unit
• Sixteen beds dedicated to the assessment and treatment of young people with a range of mental health problems which require inpatient care.
• A further two beds available in the high-dependency area for young people who require a higher level of nursing support than can be offered in the general ward.

Child and family unit
• Offers a specialist inpatient service for children aged 0-13 and their families.
• Comprises 15 inpatient beds (which includes a family flat) and up to five day places.

A system under strain: mental health problems in Northern Ireland

The number of adults and children with mental health problems in Northern Ireland is higher than anywhere else in the UK. Given that Northern Ireland also has a higher population of young people, this has resulted in a CAMHS system which is overstretched and underfunded. In 2006 a report by the Royal College of Psychiatrists stated that:

“Northern Ireland has been living with the ‘Troubles’ and the aftermath since 1969. Higher levels of socio-economic deprivation, ongoing civil strife and a higher prevalence of psychological morbidity than either England or Scotland distinguish Northern Ireland. It has been estimated that the mental health needs of men and women are potentially 21% and 29% higher respectively in comparison with England… Young people in Northern Ireland have, on average, experienced twice the number of negative life events and report much higher stress scores than adolescents in other countries.”

Michael McGimpsey MLA has stated that the recommendations contained within the Bamford Review could take 10-15 years to achieve.

The underequipping of CAMHS makes it very difficult for clinicians to provide the type of care that they strive to achieve. The specialist healthcare professionals we interviewed told us that they could achieve so much more with additional resources.

A 1999 report by Northern Ireland’s chief medical officer estimated that over a fifth of young people in the country have experienced some form of mental health problem by their eighteenth birthday.

This highlights the demand for mental health services for adults and children in Northern Ireland, something which is supported by The Bamford Review of Mental Health and Learning Disability. Unfortunately this demand has not been met with sufficient government investment to address the situation. In a written answer to a question asked by Member of the Legislative Assembly (MLA) Mr O’Loan in the Northern Ireland Assembly about the level of need in the country, the Minister of Health, Social Services and Public Safety, Michael McGimpsey, stated:

“We have a 25% pro rata smaller spend on mental health than in England, but a 25% greater need… Money had not been made available to address current underfunding in health in general and in mental health specifically.”

The Bamford Review also recommended much greater investment in CAMHS in Northern Ireland, stating in its report, “A vision of a comprehensive child and adolescent mental health service, that:

“At present the workforce profile of child and adolescent mental health services clearly shows them to be wholly inadequate. Despite many examples of good practice the overall quality, consistency and accessibility of services is so inadequate that urgent strategic action is needed to tackle these shortages.”

Although work has been ongoing in terms of the strategic development of CAMHS, the latest figures supplied by the Health and Social Care Board show that there is still a shortfall against the recommendations of the Bamford Review of ten whole-time equivalent (WTE) clinicians at specialist CAMHS (Tier 2 and Tier 3 levels).

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<th>WTE per 100,000 total population</th>
<th>Comparison with Bamford recommendations</th>
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<tr>
<td>Northern Ireland average</td>
<td>UK average</td>
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<td>10 WTE (Tier 3)</td>
<td>11-12 WTE</td>
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*There are significant resource issues for us; we are a small service.*

Healthcare professional

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1. 2006 report by the Royal College of Psychiatrists stated that 26% of the total population of Northern Ireland is under the age of 16, compared to 20% in the UK. See The Royal College of Psychiatrists (2006). Op cit


5. The Bamford Review could take 10-15 years to achieve.

11 The Bamford Review of Mental Health and Learning Disability (N. Ireland) (July 2006).

10 The Bamford Review of Mental Health and Learning Disability (N. Ireland) (May 2006).

8 Ibid

9 Ibid
Parents are often confused about how to access CAMHS in Northern Ireland, despite being desperate for support. This chapter follows the journey 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.

Of the parents we surveyed:
- over half (57%) found it difficult to get a first referral to CAMHS for their child
- over half (55%) waited over three months for a first appointment following referral. Some waited up to a year.
- two-thirds (68%) say that there have been times of crisis with their child’s mental health when they needed support, but half of these parents were unable to access that support.
- three-quarters (75%) who have children aged 14-17 say that no transition plan is in place for when their child becomes too old for CAMHS, and the majority of them worry about what support their child will receive as an adult.

Knowledge and awareness of CAMHS

Many of the parents surveyed had no real knowledge of CAMHS or how to access the services. They seemed to be unaware of the support that can be given at Tier 1, such as support from GPs, social services and teachers. In addition, many families found it almost impossible to get a referral for their child.

In order for parents to access the information and family support they need before the problems become too serious, they need to know more about CAMHS and the support they can receive. Families have asked for information and support on how to ‘spot’ mental health problems in children with autism as well as general support in dealing with autism before mental health problems occur.

We recommend

that information on the promotion of good mental health in children with autism be made available to parents by all health and social care trusts.

Satisfaction with CAMHS in Northern Ireland

In our survey of parents of children with autism, less than a third (29%) were fairly satisfied with the service they received from CAMHS, with no one being very satisfied. As discussed above, there are considerable resource issues in Northern Ireland but difficulties also arise because of the complexity of autism.

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.
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 else the interventions they provide can fail to help, and in some cases will be harmful.

“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 else the interventions they provide can fail to help, and in some cases will be harmful.”

**Training and development**

CAMHS teams in Northern Ireland can comprise of psychiatrists, psychologists, social workers, nurses and intervention therapists. If any of these professionals do not understand autism, this could impact on the quality of support that a child receives. All professionals working within CAMHS must therefore be sufficiently trained to support the needs of children with autism.

The Bamford Review recommended that:

“For some, specialist medical care and intervention will be required as appropriate. People with autism should receive this from medical practitioners trained in an understanding of autism... Those responsible for service commissioning and delivery will need to keep abreast of current developments, research and efficacy of interventions for autism.”

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

In our survey, parents who told us that someone who understood autism had been involved in the support their child received for their mental health problems were seven times more likely to say that CAMHS were able to communicate with their child and twice as likely to be satisfied with the support they received from CAMHS.

Specialist autism expertise must be available to all children with autism and mental health problems, wherever they happen to live. CAMHS professionals must have a good enough understanding of autism to identify and support these children and make appropriate referrals to specialists where necessary.

“We are seeing much more complex presentations and that is going to be a significant challenge to us all to be able to meet the needs of those complex presentations. There are significant challenges and we are going to have less resource to do it.”

Healthcare professional

“Training and development”

The Bamford Review of Mental Health and Learning Disability (N. Ireland) (May 2006). Op cit

**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.

“Training and development”

The Bamford Review of Mental Health and Learning Disability (N. Ireland) (May 2006). Op cit
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 emergency appointments (83%), a 24-hour helpline (72%) and on-call home visits (56%).

The following case study from a 2010 judicial review highlights a number of failings in the system in relation to assessment and crisis intervention, and shows the impact that mental health problems in children with autism can have on the whole family.

Judicial review highlights issues around mental health in children with autism

A judicial review carried out in Northern Ireland in 2010 called for a reform of the way children and families receive care. Mr Justice Treacy found that the Western Health and Social Care Trust had acted in breach of its duty of care to carry out assessments and provide services to the carers of disabled children.

The review focused on a case involving a young man with autism and ADHD who had psychotic tendencies and an intense dislike of females, especially his younger sister. Both the boy and his sister had been placed on the child protection register because of the danger he posed to himself and his sister.

A social worker employed by the Western Trust to carry out a carers’ assessment on the boy’s mother in 2008 recorded that she had had a complete breakdown as a result of her role as a carer. Despite this, the mother heard nothing for four months and was subsequently informed that there was no budget available to meet their assessed needs.

In late 2008 the young man made a series of threats against his sister. On Christmas day 2008 he tried to hang himself in the family home. “I telephoned the out-of-hours emergency number for social services but they were unable to assist,” said the mother.

Following his suicide attempt, the young man was admitted to Minnowburn House in Belfast for assessment. However, he still returned home at weekends and his mother struggled to manage his needs and had difficulty transporting him to and from Belfast.

Despite these ongoing difficulties and a legal duty to provide services, provision was not put in place to assist the mother.

Waiting times

Following referral, almost a quarter of parents we surveyed waited over 18 weeks for their first appointment and a further 16% waited 13-18 weeks. Parents told us about waiting to see specialist professionals for over a year because of a lack of local provision, changes in staff, and long waiting lists.

“We have been waiting an extremely long time for a clinical psychology appointment and in the mean time have been through extreme eating problems, resulting in our child being ill and needing hospital treatment. Yet he is still on the waiting list.”

Parent of a young child

“We had a referral to CAMHS but we got a letter back to tell us that there would be no one in post until the end of the year and therefore the children couldn’t be seen! We don’t know at this stage if they will be placed on a waiting list when the post has been filled or if we have to start all over again. Autism is the poor relation of the health service – it is way down the list of priorities in both health and education.”

Parent of a young teenager

We recommend that health and social care trusts develop specific pathways for mental health support for children with autism.

Pathways for referral and care

The parents we surveyed felt that waiting lists for referrals and appointments had a negative impact on their children’s mental health. Many parents were confused about the CAMHS pathways for referral and care. The routes in for children with autism to get support for their mental health problems are not always clear.

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Christopher

Christopher is 16 years old and was diagnosed with Asperger syndrome when he was seven. He was referred to CAMHS by his GP at the age of three because of his behavioural difficulties.

A lot of Christopher's difficulties were originally thought to be a consequence of having been sexually abused by an older child. When he was 11 he tried to take his own life. His mum thought this was due to the difficulty he experienced transferring from primary to secondary school. Christopher spent a year out of school. He developed an eating problem and is now classified as clinically obese. He has difficulties with changes in routine and in his personal care, often refusing to wash or get dressed.

Christopher spent six months in Minnowburn Hospital (a Tier 4 inpatient unit, now replaced by Beechcroft) but continues to experience mental health problems. His mum feels that provision for her son has improved since his suicide attempt. “They are at the end of the phone. I find them very good.” However, while she feels supported now, Christopher’s mum is very concerned about the transition from CAMHS to adult services.

Support for families

The remit of CAMHS includes support for the whole family. This might be through family therapy sessions or advice and coping strategies designed to help family members deal with a child’s mental health problems at home and 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, contribute to the child's recovery and prevent family breakdown. But only a quarter of parents felt that CAMHS sufficiently supported family members who needed help.

It is crucial that the Northern Ireland Assembly recognises the impact that mental health problems in children with autism can have on a family, and that commissioners recognise CAMHS’ responsibility to support the whole family, not just the child.

“I think more should be done to inform parents of an autistic child of what help is on offer and how to deal with the difficulties our children have.”

Parent

“There should be parent workshops offered to support families.”

Parent of a young teenager

Transition to adulthood

“Transition between CAMHS and adult services had an abrupt cut-off at age 18. The young ASD person in our family does have access to an assistant Asperger's worker but has no overall specialist psychiatrist for his condition... This leaves me as his carer feeling extremely vulnerable because I feel he is not getting what might be available within the UK (or global for that matter) and I think if he got the right help now it may stop the condition becoming more entrenched as he reaches adulthood.”

Parent of a young adult

Moving into adulthood is a very important time for all young people with disabilities 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 is simply not happening.

In our survey, all the parents of children aged 14-17 told us that their child requires ongoing mental health support. Almost all parents worried about what mental health support their child would get when they turned 18. The vast majority of these parents, and the parents of those aged 18-21 who require 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.

All the health and social care trusts told us that they did plan for the transition from CAMHS to adult services. However, parents who responded to our survey did not appear to be aware of this process. Yet our previous research among adults with autism in Northern Ireland, I Exist, showed that 34% had experienced serious mental health problems as a direct result of a lack of support.

In England, there is a new duty on CAMHS to ensure that protocols are in place in every local area for the transition of clinical mental health care for children with autism in receipt of CAMHS. We recommend that similar duties be implemented in Northern Ireland.

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Joe is seven years old and was diagnosed with Asperger syndrome in 2009. He displayed quite a lot of anxiety and his mum was worried about his mental health, so she asked for a referral to CAMHS. His mum says:

“Joe was very low self-esteem, despite all the things that we try to make him feel great about himself. We are forever highlighting things that he does well but Joe will always find a negative aspect to everything that he does. He will always compare himself to somebody else who maybe would have done something better. I could see that he was really down and negative about himself. He talked about how he wanted to die, how he didn’t want to be in our family any more and how he wanted to go away and live on his own and all of this kind of thing, and he was only six, so obviously there were some major problems there.

"I spoke to the paediatrician and said that I was really concerned and that I wanted some help, some professional advice for these outbursts, because I was petrified about what I was saying [to him]. Maybe I was making him feel worse or something, so that is why we were referred to CAMHS."

Unfortunately Joe’s appointments with CAMHS are only every couple of months and the clinicians seeing him have changed on a number of occasions, so they have never really got to know him. Other than this, Joe has only received what his mum describes as “counselling-type therapy”.

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 (42%) of parents think CAMHS staff know how to communicate with their child.

Communicating with children with autism requires flexibility, patience and skill. Children with autism are likely to take longer than other children to gain trust in the professional and to communicate openly. A willingness by professionals to adapt the way they work 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. Many people with autism have a very literal understanding of language, and think people always mean exactly what they say. Therefore, 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.

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.

Some children with autism find it much harder than others to express their feelings. This often results in them keeping things bottled up or pretending that everything is fine. 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.

“My son is seeing an associate psychologist but I see no improvement in him. I don’t think she knows much at all, but I don’t know how to get someone else.”

Parent of a young teenager
**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.

Furthermore, a child’s mental health problems can be ‘over-shadowed’ by autism if professionals are unable to distinguish between the two and regard mental health conditions, for example anxiety, as an inevitable and unavoidable side-effect of autism. When a child with autism also has a mental health problem, it is therefore crucial that they get the right diagnosis. If a child is wrongly assessed, then the wrong support inevitably follows.

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**Geraldine**

Geraldine has six children, three of whom have autism. Accessing CAMHS services for one of her children proved extremely difficult for her. Geraldine says:

“No one listens. I knew that my son had difficulties from the age of about two and we have struggled to get his difficulties recognised. He was seen a range of professionals for years.

“Eventually in 2007 he was seen by the CAMHS in my area after a referral from my GP, as he was suffering from extreme depression. However, he was dismissed as being a ‘typical teenager’. Eventually, after a 17-month wait, he was diagnosed as having autism and learning difficulties but we as a family have had no support. The only person that has helped us is The National Autistic Society’s family support worker.

“My two other children who have autism are also experiencing anxiety and depression. My daughter spent most of last summer in her bedroom and is frightened of going out; the only place she goes to is school.”

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**Paul**

Paul is 14 years old and was diagnosed with Asperger syndrome at the age of five. He suffers from anxiety, depression and has suicidal thoughts, yet even though he has been seen by CAMHS, mental health professionals have been unable to help.

Following his diagnosis, Paul was referred to see a clinical psychologist but he refused to cooperate with them and so was discharged, as the practitioner didn’t see any point to the sessions continuing. He now receives no help from CAMHS.

**Involving parents**

Parental involvement is essential when treating children with autism and mental health problems. However, many parents we surveyed did not feel involved in the process.

“We have had approximately six appointments with CAMHS in the last year, during which our problems have been discussed. At no time have we been offered any form of specific therapy (eg art therapy, occupational therapy, music therapy, etc), even though my child has clear sensory processing and perception difficulties. The possibility of medication was discussed at an early stage but I declined, explaining that I would prefer to explore other support options. Nothing else has been offered.”

Parent of a young adult

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**Case study: EASI project in the Southern Trust**

The EASI project, which stands for: emotions, autism and sensory integration, was an initiative of the Southern Trust. It brought together clinicians from CAMHS, occupational therapy and social work, and also involved Craigavon Council.

The project worked with young people with autism who were known to CAMHS and had difficulty understanding and managing their own emotions and who also had sensory processing difficulties.

The programme aimed to enable young people to better understand themselves and the physical symptoms associated with their anxiety and emotions. It also aimed to help them learn how to regulate and to alleviate some of these symptoms through physical activity, which would also serve to address their sensory difficulties. The physical activities were recommended by the occupational therapist to address the need for deep pressure and included trampolining, circuits, archery and horseriding.

Because parents stayed while their children took part in these activities, an informal support group formed in which parents talked to each other about the difficulties their children were experiencing.

The project was extremely successful in reaching young people who found it difficult to engage with others and to participate in activities. The Southern Trust hopes to roll this project out to other localities.
Developing key autism specialists in CAMHS

All CAMHS staff need to have a broad understanding of autism to ensure that children receive appropriate support. However, providing mental health support to children with autism is a specialist skill. Without that specialist level of knowledge, it can be difficult to treat these children. It is therefore vitally important to have autism specialists in CAMHS who can help other professionals to develop their own skills. A variety of professionals can be autism specialists. Within CAMHS these are often psychiatrists or psychologists. A specialist will have an excellent, in-depth working understanding of autism and would be expected 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.

“A lot of CAMHS staff are saying we have all of these interventions that we would use with this particular mental health problem but it doesn’t work when you have someone with autism.”

Healthcare professional

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.

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 aids, increasing the emphasis on practical coping strategies, and reducing the use of abstract language.16

We recommend

that key autism specialists are identified in each CAMHS service and play a lead role in developing staff training and act as a source of specialist advice.

We recommend
that health and social care trusts record data on the mental health needs of children with autism in their local area.

Planning services
As outlined earlier, there is limited research into the prevalence of mental health problems in children with autism in Northern Ireland. The collection of data on children and adults with autism has been problematic. There has been no uniformity in the type of data recorded and different systems operate in different trust areas. Commissioners have a duty to understand the care and support needs of the local population and to commission services to meet those needs.

Commissioners need to know how many children with autism live in each health and social care trust area and what their mental health needs are. In Northern Ireland, health and social care trusts are beginning to record the number of children with autism in their local area. However, they also need to ensure that they record their mental health problems. This data can then be used to plan the right services for these children.

Data also needs to be recorded on how well CAMHS services are working for children with autism. Waiting lists for children with autism and mental health problems need to be monitored alongside the outcomes for these children and their families. This would allow commissioners to understand how successful their services are in helping children with autism.

Inpatient units (Tier 4)
The children who use Tier 4 CAMHS have the most complex or serious mental health needs and will usually be extremely vulnerable. 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 imperative that the children with autism 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 ad-hoc social activities such as day trips etc, 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 adjustments.

Because of the complexity and vulnerability of children with autism who use Tier 4 CAMHS, any service failure can have a devastating impact on them. A specialist understanding of autism is vital.
How direction from the Northern Ireland Assembly can make a difference

An understanding of the issues must not begin and end with frontline professionals. As outlined previously, their dedication to providing the right support can be undermined by a lack of resources.

In Northern Ireland there have been a number of initiatives to address the lack of services for children and adults with autism and their families and carers. In June 2009, Michael McGimpsey MLA published the Autism Spectrum Disorder (ASD) Strategic Action Plan, which arose from the independent review of autism services chaired by Lord Maginnis. The minister commissioned the RASDN to take forward the implementation of the strategy with Dr Bergin and Lord Maginnis heading up the process.

The RASDN comprises of a network of parents and carers, people with autism and voluntary and statutory sector representatives who are working together to devise services that best meet the needs of people with autism and their families and carers. Parents and carers are officially mandated as advisors to the Reference Group and each trust. They are involved in all recent investments and in service improvement. The RASDN is working well and we are starting to see outcomes from the group, such as the appointment of ASD co-ordinators and support staff within the Southern Trust, Belfast Trust and, recently, the Northern Trust.

There has been a recurrent investment of £1.54 million in RASDN over the 2009-2011 period, which will rise to £1.64 million from April 2011. Although this investment is welcome, it will not address the historic under-spending in autism services in Northern Ireland. There have been improvements in other areas, such as a reduction in waiting times for assessments to 13 weeks (four out of five health and social care trusts have met this target), the development of a children’s diagnostic pathway as well as an adult pathway, and developments in the areas of training, interventions and transitions.

We recommend that the RASDN identifies a CAMHS workstream to reform the provision of mental health services for children with autism and their families.
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 that CAMHS in Northern Ireland is underfunded and overstretched. And we have learned that children with autism and their families and carers struggle to access the right support – often when it is most needed.

Summary of recommendations

Education
We recommend more training for education professionals, such as teachers and classroom assistants, to enable them to implement strategies and create an ethos of understanding which will benefit children with autism.

Knowledge and awareness of CAMHS
We recommend that information on the promotion of good mental health in children with autism be made available to parents by all health and social care trusts.

Better understanding of autism in the system
We recommend that all staff working in CAMHS tiers 2, 3 and 4 have basic training in autism and access to specialist advice.

Pathways for referral and care
We recommend that health and social care trusts develop specific pathways for mental health support for children with autism.

Transition
We recommend that a statutory duty be introduced to ensure that protocols are in place for the transition of children into adult mental health services.

Interventions
We recommend that key autism specialists be identified in all CAMHS and that they play a lead role in developing staff training and act as a source of specialist advice.

Planning services
We recommend that health and social care trusts record data on the mental health needs of children with autism in their local area.

Regional Autistic Spectrum Disorder Network
We recommend that the RASDN identifies a CAMHS workstream to reform the provision of mental health services for children with autism.
The research for *You Need To Know* involved three main stages of work, as described below.

A. Interviews with professionals in the health and social care trusts

The National Autistic Society Northern Ireland carried out face-to-face interviews with representatives of the four health and social care trusts responsible for delivering CAMHS in the five health and social care trust areas in Northern Ireland.

B. 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 with autism (including Asperger syndrome) of mental health services, via their parents and carers. 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.

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.

Sample

A total of 109 responses were received from parents and carers of children and young people with autism.

C. In-depth face-to-face interviews

We conducted four in-depth interviews with parents whose children had been diagnosed with autism and had co-occurring mental health problems.

The research for *You Need To Know* was based on the experiences of 109 families in Northern Ireland. It provides a snapshot of the mental health problems that children with autism in Northern Ireland are experiencing. It is not a comprehensive analysis of the situation. Rather, it reflects the experience of these families and seeks to make their voices heard.

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1 We asked parents to respond if they had a child with autism aged 0-21.
2 People with autism aged 16-21 were also invited to complete the survey.
The National Autistic Society Northern Ireland is part of the UK’s leading charity for people affected by autism.

Over 17,000 people in Northern Ireland have autism - that’s one in 100. Together with their families they make up over 68,000 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.