Consultation Report

The National Autistic Society
South Hampshire Branch

Autism and Mental Health Consultation

In partnership with:

Hampshire Autism Voice

With the assistance of:

Autism Hampshire

Funded by:

healthwatch Hampshire

Until everyone understands

Contents

Introduction

In October and November 2016, the South Hampshire Branch of the National Autistic Society (a self-funded voluntary group run by parents of children, young people and adults with autism) carried out a consultation about the way in which mental health affects children and adults with autism, and accessing services in Hampshire in the last 3 years. The consultation was funded and supported by Healthwatch Hampshire. The project was aimed at children, young people and adults with autism, their families/carers and professionals who work with them.

The branch worked in partnership with Hampshire Autism Voice (HAV) – the voluntary parent/carer/people-with-autism group on the Hampshire Autism Partnership Board (HAPB). Autism Hampshire was commissioned to facilitate focus groups and one-to-one interviews.

The consultation consisted of an online survey created on 14 October 2016 through the Hampshire Autism Voice Network. Survey links were distributed in the NAS branch newsletter and by Autism Hampshire, Parent Voice, Hampshire Parent Carer Network and Hampshire County Council. 146 people responded.

At the same time, two focus groups for parents and carers took place, one at a NAS South Hampshire support group meeting in Bishopstoke and one at the Brunch Club in Basingstoke. In total 36 people attended. There were seven 1:1 telephone interviews conducted with 6 adults with autism plus a parent of an adult who have accessed mental health services in Hampshire.

Once the online survey had closed, the initial results were discussed in a focus group with professionals to discuss their views. This group consisted of Mental Health professionals, Hampshire County Council and Healthwatch Hampshire representatives.

There will also be a film made about the results, using footage from the focus groups and some interviews with participants, which will be available following the publication of this report.

This report will be distributed to Healthwatch Hampshire, and then to HAPB, the Department of Health Autism Lead, and any other useful channels.

Please note: the terms ASD, ASC and Asperger syndrome mentioned throughout this report all refer to autism.

Summary

What is mental health to a person with autism?

We asked how people who have experience of autism view mental health in general. What is good mental health, and what is poor mental health? Do people with autism view mental health in a different way? Most of the people who responded associated good mental health with being happy, calm and confident and being able to cope with life. Conversely, poor mental health is associated with feeling overwhelmed by fear, stress, sensory overload, emotions and situations, leading to crippling anxiety, depression and other problems.

Good mental health means	Poor mental health means
being happy	being overwhelmed
being in control	being anxious
being sociable	difficulty coping with life
being calm and letting anxiety go	not being able to leave the house
being able to cope with life	difficulty coping with emotions
being able to solve problems	being unable to interact with others
being independent	anything other than “normal”
being accepted	not fitting into society/social isolation
having self-esteem and confidence	not coping with changes to routine
being rational	low self-esteem
being normal	depression
being able to communicate feelings and needs	Obsessive Compulsive Disorder
being emotionally resilient	agoraphobia
being able to form and maintain relationships and friendships	Bipolar Disorder
having a sense of purpose in life	Social Communication Disorder
	schizophrenia
	paranoia
	self-harm
	eating disorders

In the online survey, we asked if the people with ASD would be able to recognise if they had a mental health problem and seek help for themselves and 52.4% of people with ASD said yes they would be able to, but only 21.7% would be able to seek help for their problems. One person said that *“it was very difficult and I had to write to my GP as I couldn't verbalise it”*. Only 27.4% of the parents and carers felt that their person would be able to recognise it, and only 5% would be able to seek help independently mainly because they were responding about children who were too young to recognise it or seek help, but also for a range of other reasons:

- they wouldn't know where to begin
- rarely get moments of clarity
- caught up in own world
- anxiety prevents interactions
- ability varies on a daily basis
- to them it's normal
- not enough patience to go through the system
- selective mute
- cannot communicate well enough

Sources of information and support

The most common pathway that people took to get support was through their GP (87.5% of people with ASD and 84.3% of parents/carers [online survey]), and then referral to CAMHS (71.4% of people with ASD and 74% of parents/carers [online survey]). Other sources of help and support were:

NHS: • Adult Mental Health • Community Mental Health Team • Community nurse • Early Intervention in Psychosis Service • Paediatrician	**Hampshire County Council:** • Children with Disabilities team (Social Care) • Community Learning Disability Team • Hampshire Portage Service • Social Services	**Other:** • Connections with other families and likeminded people • Friends • Incontinence service • Individual specialist (e.g. psychologist, SALT, OT) • Police • Safe place • School – ELSA, school nurse, SENCO • Sleep clinic • Support worker • University counsellor • Serendipity social group
Charities: • Autism Hampshire • Enham Trust • Fareham Mind • Mind • Mustard Seed Autism Trust • NAS Branch & associated social groups • No Limits • Winchester Youth Counselling	**Services:** • Autism Diagnostic Research Centre • Eastleigh Youth Counselling Services • italk • Maple Ridge Outreach (specialist school) • Private psychiatric and psychological services	

Ease of access to mental health services for a person with autism

Many people felt that getting access to mental health services was very difficult (46% of people with ASD, 54.3% of parents/carers [online survey]). Initial referrals were often quick, but waiting times to be seen are too long – in the online survey, over half of respondents have had to wait over 12 months to access any mental health service (54.2% of people of ASD, 50.5% of parents/carers [online survey]). One parent told us *“It took me 13 months to get an appointment with CAMHS. My son could have been dead by then”*.

In our online survey, 13 people reported that they were declined by or not referred to their local CAMHS because they or their person had autism. One parent was told by CAMHS that his son’s *“high level anxiety and eating issues…were 'not' a mental health issue (because) they were linked with the Aspergers/ASC”*.

Six of our respondents have told us that mental health services either refuse to help or say they can’t help unless the person has reached crisis point (e.g. self-harming, attempted rather than threatened suicide). One parent said of her daughter that *“CAMHS said they wouldn’t do anything until she actually did self-harm”*.

Others report difficulties with communicating their needs to gain a referral. Often the only way to contact CMHT, for example, is by phone but some people with autism find speaking on the phone difficult and distressing, and they lack flexibility to seek other ways to make contact. Being able to make appointments online for some services has helped, but only for those who have access to the internet.

Professionals, at their focus group, recognised the need for some sort of preventative measures for individuals who do not qualify for Advocacy or CAMHS services, in order that people do not end up in crisis.

How do mental health professionals treat a person with autism? Do they understand autism?

Some of our respondents report that what has helped when seeing a mental health professional is being listened to, and in our survey 40.6% of people with autism and 34.1% of parents and carers have agreed that the person they saw listened carefully to them. However, sometimes professionals do not listen because of the person’s communication difficulties. One parent told us *“people won't listen properly to her as she can't verbalise her needs. It is easier for professionals to just guess what they want you hear rather than help”*.

One of our interviewees said that they need to know more about what to expect during appointments and treatment, to help reduce anxiety. She said of her appointment that *“I was terrified – not knowing what was going to happen, who was going to speak to me. I didn’t know what they meant by assessment”*.

What has not helped is professionals not being able to separate autism from mental health difficulties. Autism is often blamed for their issues, and conversely autism can be masked by a mental health issue leading to misdiagnosis. One parent said that her daughter was thought to have borderline personality disorder (BPD), before being diagnosed with autism. Professionals also don’t routinely ask about autism so some people with a diagnosis don’t disclose because a direct question is not asked.

Lack of awareness or understanding of autism amongst professionals has also not helped. One person with autism felt that *“some of things said to me were not explained enough and did not take into account my difficulty with verbal processing”*. Another said that *“they admitted to not understanding autism, and said they might be able to learn from my case”*, and another said that *“they didn't know how I could have autism because I ‘could speak’ so I had to explain to her”*.

At the professionals’ focus group it was identified that professionals are not always clear what is the most appropriate course of action. There is also awareness that professionals sometimes tell people with autism how they should think. Professionals also recognise that autism awareness and understanding needs improving among staff and this should be an ongoing process.

Experiences of mental health services

Some examples of positive experiences from using mental health services were the speed of being seen, having a consistent approach with the same consultant, being seen by compassionate and helpful staff, and having someone there to talk to. Six people said that what helped was using private consultations and therapy, for example the Autism Diagnostic Research Centre (ADRC), to avoid long waiting lists.

What has not helped is being discharged from services if the person shows improvement in their condition, and then having to wait to get back into the system if they regress or reach crisis point. Continuous low level treatment would have helped in these situations.

Some reported a difficulty with accessing autism specific services, such as counselling.

What treatment/support is available for a person with autism, and what has helped?

There was a wide range of treatments, therapy and support used by people with autism that have helped. One person was able to see a *“highly experienced clinical psychologist with wide ASD experience”*. One has attended a local autism specific social group. A number had received Cognitive Behavioural Therapy (CBT), which had mixed results, depending on the individual.

Seven people were referred to italk, a telephone psychological therapy service, which did help some but one person with autism said that it is *“not very practical for someone who doesn't like speaking to strangers on the phone”*, and another that *“it still didn’t change my behaviour. It doesn’t change my rigid thinking”*.

Professionals recognise that italk may not be the most appropriate treatment for some people with autism. At the professionals’ focus group it was suggested that there should be a greater focus on teaching people skills to ‘enable’ rather than care or support, i.e. a strength-based approach.

Medication has been a benefit to 9 of our respondents, but 6 others have refused it or have had problems with getting the right medication, the right dose or have struggled with side-effects.

Transition to adult support

In our online survey, of the 27 parent/carers who answered this question, 11 said that they had had no transition. One interviewee’s son had a very abrupt discharge. Of those who did go through the transition, only one person said it went well. Another said that it was *“absolutely disastrous”*, another that they did not receive any services after transition, and another said they had a transition meeting, was discharged, then they *“had to wait for crisis before beginning a new referral and start at the bottom of the waiting list again”*.

The impact of mental health problems and autism on the person’s family

While three respondents said they have been able to cope so far and report no impact and one person commented that *“we have devised coping strategies ourselves to make our family stronger”*, the majority of the comments outline a negative impact on family life. This can be summarised as follows:

- marital problems –separation, arguments
- depression
- stress, increased anxiety
- restricted activities
- exhausted due to lack of sleep, run down
- gave up work/unable to work due to caring for person
- siblings feel responsible, leading to stress
- one person reported taking medication to cope
- loneliness due to social isolation
- violence towards family
- existing physical conditions worsened
- concern about what happens when the parent/carer dies?

A common theme from our respondents is that living with a person with mental health problems and autism is *“mentally draining and physically demanding”*, and it has *“taken over our lives”*.

Recommendations

of how mental health services and access to them can be improved

Based on the responses we received from the consultation, our recommendations for improvement are as follows:

1. **Better communication:**
    a. Explain what is going to happen in advance to reduce anxiety (verbally, visually including with photos, use social stories).
    b. Make contacting services easier by providing options to text, email or book online.
    c. Explain clearly the benefits and side-effects of medication.
    d. Improve the referral process and waiting times for appointments. Also improve continuity for individuals once referred.
    e. Listen to and respect the views of the patient and/or parent.
2. **Better autism awareness, training and understanding:**
    a. Be more accepting and positive about autism – it's not bad, it's just different.
    b. Ensure practitioners and front line staff have a good knowledge and understanding of autism, to avoid miscommunication, misdiagnosis, and inappropriate treatment.
    c. Include autism as part of initial professional training.
    d. Make use of the Autism Ambassador Scheme.
    e. Improve understanding by CAMHS and CMHT that a person can have both autism and mental health issues.
    f. Provide ongoing continuing professional development – perhaps include legitimately as part of safeguarding training?
    g. Provide better awareness, understanding and support information about mental health and autism, for people with autism and their families.
3. **Improvements to post-diagnosis**
    a. Open up the current CAMHS autism support sessions (run in conjunction with Autism Hampshire) to other families, not just those on the waiting list or recently diagnosed.
    b. Use personalised, 'strength-based' approach, enabling rather than care and support. Teaching people how to make their own solutions.
    c. Provide better transition from CAMHS to adult mental health services, especially for those using medication.
4. **Improvements to services**
    a. Consider autism when commissioning services. Autism professionals need to be involved; in particular, HCC autism leads.
    b. Provide an autism pathway within mental health services, staffed by a specialist team.
    c. Look at more appropriate pathways for autism diagnosis for children and young people.
    d. Provide continuous low-level support or treatment to avoid escalation and crisis.
    e. Put in place preventative measures to help those who don't quite meet the criteria for Advocacy and CAMHS services, to avoid escalation and crisis.
    f. Ensure a person-centred approach is adopted as not all issues are due to autism; other factors should be considered.
    g. Mental health services to make available and offer support to the whole family if needed.
    h. Flag/alert on patient records so front-line staff know a person has autism.
    i. Consider using different ways of sharing information between professionals, for example, webcasts, Skype and video consultations.
    j. Publish information in a more accessible and informative way which is user-friendly for people with autism.
    k. Public Health should look at autism in different cultures – with strong extended families, providing structure.
    l. From this consultation's results, develop autism best practice guidance for professionals.

Results from parent/carer/people-with-autism focus groups and interviews

2 parent/carer focus groups were held in Eastleigh and Basingstoke with a total of 36 participants.

6 adults with an ASC, plus a parent of an adult, were interviewed in late 2016/early 2017.

All sessions were semi-structured.

What does good mental health mean to you?

When asked what they considered to be good mental health, participants talked about the following:

A standard range of emotions – no extremes	Good focus
Ability to cope with what life throws at you	Good self-care
Ability to enjoy aspects of daily life	Good self-esteem and well being
Ability to solve problems in a rational way	Happy and healthy
Ability to take steps to look after your own well being	Having a sense of purpose in life
Able to carry out normal tasks independently	Integration in society
Able to give and take in a balanced way	Less outbursts
Absence of negative issues	Logical
Acceptance	Maintaining the same mind set when something stressful happens
Appropriate self-esteem/confidence	Manage to cope with daily activities
Basic rationality	No irregular obsessive behaviour
Be able to do what I like – going out where and when I want to without anxiety	Non-threatening to others
Be normal, not noticeable	Not being overly controlled by emotions
Being able to communicate your feelings and needs	Not experiencing emotional extremes
Being in control	Not having to want or need access to mental health services help
Being out and about and interacting	Not wanting to find myself sitting in a corner – wanting to engage with other people
Calm and collected able to handle situations without getting upset	Opportunity for growth
Having confidence	Same worries, but more able to cope
Contentment	Satisfaction with life, no desire to commit suicide or self-harm
Emotional resilience and stability	Satisfaction with what you are doing/achieving
Able to engage in activities	Self-belief
Feeling needed	Self-worth
Fitting in	Speaks normally
Form and maintain relationships	Having a vision for the future
Friendship and social interactions	

What do you consider to be a mental health issue?

Participants talked about the following in relation to poor mental health:

A feeling of not wanting to get out of bed	Lack of motivation
Abrasive attitude	Mood swings
Agitation	Needs other around them – craves attention
Agoraphobia	Not taking care of self
Anxiety	OCD
Bi-polar and other illness	Overwhelmed
Can't cope with change of routine	Overwhelmed by catastrophisation
Can't cope with life	Overwhelmed by thought and sensory overload
Can't go out when I want to	Paranoia
Can't stop thoughts going round	Persistent unpleasant thoughts and feelings

Cry for nothing – it just happens	Physical abuse and violence
Depression	Physical symptoms such as tiredness, headaches, feeling sick, lethargy
Difficulty coping with relatively mild tasks	Reckless behaviour
Difficulty with day to day tasks and routine	Reclusive
Drained and tired	Self-harm
Feeling hopeless	Stopping relationships with others
Feeling numb	Stress
Feeling very anxious and emotional	Substance abuse
Feeling worthless	Suicidal thoughts
Frustration	Takes over all other things in life
Inability to cope with what life throws at you	Thought patterns highly dictated by emotions
Instability of ability of managing emotions (outside of the accepted norm)	Too anxious to go somewhere new or meet new people
Irregular eating and sleeping patterns	Verbal and physical behaviour not normal
Irritable, likely to lash out and lose temper	Warped/ skewed view of the world
Lack of awareness of condition	Ability to function is impaired
Lack of coping skills	

Sources of information and support

Participants talked about a number of different sources where they had either sought help themselves or been referred, for example, through their GP.

Community Mental Health Team (CMHT)	No limits
Adult mental health inpatient	University counsellor
Child & Adolescent Mental Health Service (CAMHS)	italk
Community nurse	Autism Hampshire
Doctor/GP	NAS Branch and associated social groups
Paediatrician	MIND
Social Services	Serendipity group
Support worker	Connections with other families and likeminded people
Reablement team	Friends
Autism Diagnostic Research Centre (ADRC)	Safe place
Private psychiatric and psychological services	School – Emotional literacy support assistant (ELSA), school nurse, SENCo
Counselling services	Police
Winchester Youth Counselling	

What has helped?

- People listening to what the parent/person with autism says and needs. A parent of an adult felt that being listened to was important: "*Those who listen and are autism aware are- best – some staff are better than others.*"
- Support and services to help with day-to-day life, which take into account autism. A parent of a young adult with autism talked about their positive experience with a support service. "*We had really good support from the Reablement team, … who we were referred to by the adult mental health service. My son attended residential school until he was 19 yrs. He had real trouble adjusting to being at home and wouldn't accept me as his teacher… It really has improved his mental health by giving him control over some things in his life.*"
- Local autism specific social and support groups were mentioned as helpful by a number of people. An adult talked about joining a local social group: "*Something that has helped is the Serendipity Social Group. It's the only thing I have. I started when the group started, but I have found them to be such a great thing.*"
- Paying for private consultation and therapy has really helped some people, particularly where long waiting times or lack of available services meant there was nothing available when it was needed.

- Professional staff with good autism understanding, not just awareness. An adult with autism talked about her first appointment with a CMHT psychologist: "*The psychologist thanked me for telling her I have autism. She told me it would affect how she would treat me. She is the first person I met who has been very positive about my autism.*"
- Sensory needs being understood and met.
- Autism specific or tailored therapies.
- Being able to make appointments online. One adult had found their local GP surgery's online booking service really helpful, although often this is only available for appointments booked in advance, not for more urgent appointments.
- italk – works for some but not all. The same applies to Cognitive Behavioural Therapy (CBT). A number of interviewees had been referred for CBT and/or italk. Their experiences varied, as each is an individual and what works for one person may not for another. One adult talked about their experience of italk: "*I am presently doing italk which is very helpful. With the psychiatrist I was just seen every now and again. With italk I'm seen every week, which is helpful.*"
- Medication – works for some but not all. There are also concerns around pre-conceived views of medication by individuals, and personal choice. An adult stated how his view of medication changed: "*I was VERY wary of meds, but it has really helped.*" This is not always the case though.
- GPs – some very positive experiences related to listening and acting on patient concerns around autism and mental health. This is also linked to knowing the person well.
- Help from the Reablement team
- Local autism-specific professional services, such as ADRC and Autism Hampshire were reported as very positive experiences. One parent talked about their experience of ADRC: "*We had a very positive experience with the ADRC, which we funded privately. They were brilliant…. They gained my son's confidence within seconds and it was great that they spoke directly to him while I listened.*"

What has not helped?

- Lack of autism understanding, or even awareness in some cases, amongst mental health professionals. Many people had experienced professionals lacking understanding of autism. Some had little awareness other than general misconceptions around autism. One adult stated that "*I often find people talk to me like I'm a child or stupid – I'm not stupid, I have autism.*" This area in particular appears to be at the root of much of the difficulty people have with mental health services. Participants also reported problems around assumptions being made about themselves by professionals. One adult with autism said that "*I think the CPN didn't know very much about autism at all. She didn't seem to believe that I could be autistic because I have a good vocabulary, can speak and have a good education.*" Autism-related difficulties, such as sensory issues were also not always taken seriously. One adult with Asperger syndrome, when attending an emotional coping skills course, was *"…very distracted by sensory issues."* As a strategy to help, she removed her shoes and rubbed her feet on the floor, for sensory feedback. *"The course organisers commented about it and seemed to think it was funny. I don't think they knew enough about autism to understand why I needed to do it.*"
- People not being listened to or even believed. Most people interviewed had experienced not being listened to, or believed, in relation to mental health difficulties, sometimes on multiple occasions from different professionals.
- Autism being 'blamed' for their difficulties. Dismissal of the idea that there could be a mental health issue too. Sometimes the opposite (autism is masked by mental health issue), leading to misdiagnosis, due to lack of understanding of autism. A parent interviewed on behalf of her adult daughter, said "*They [CMHT] realised that her issues such as meltdowns were related to autism. Before they thought she had borderline personality disorder (BPD).*" Professionals also don't routinely ask about autism so some people with a diagnosis don't disclose because a direct question is not asked.
- Problems with communication. Often the only way to contact the CMHT, for example, is by phone, but this is difficult for some people with autism. Compounded by a lack of flexibility, so there is no other way to contact mental health services. An adult with Asperger syndrome talked about how she felt about this: "*There is a crisis line, but what would happen if you called it was not explained fully, so I didn't use it. Also, you have to be able to make telephone calls when in crisis which I don't think I could have done, but there was no other way to get help without using a phone.*"
- Reported difficulties accessing autism-specific services, such as counselling.
- Lack of continuity – being passed around different people within a service. Also being passed around different services within CMHT. Many of the people interviewed had problems with continuity of mental health services. One young adult with Asperger syndrome was frustrated by the lack of continuity of people involved. "*I had an initial appointment with CMH in April 2014, after that I was passed round and round – I saw about 8 different people. To start with it was a relief*

to get there, but then on the first appointment they said there wasn't much they could do for me. Later they frequently said they were not an autism specific service."

- Therapies are often just 6 weeks, with nothing to follow-on, this is seen as not long enough by many of the people interviewed. There is also a lack of flexibility and therapies offered are often not personalised. One adult felt that there should be something more long term. "*After many years of mental health problems I was looking for a long term therapy to get to the root of the problem. CBT and mindfulness didn't help. You had a 6-week programme which was totally ineffective…. What the CMH team did felt like re-tiling the roof – a short term quick fix.*"
- People are being discharged from mental health services either with no warning or after a short time and no actual resolution in their mental health. One parent talked about her teenage son: "*I had a phone call on my son's 16th birthday from CAMHS to say he was being discharged from their service.*" Some are also discharged if they improve, even slightly but often cannot maintain this and slip back again. A number of people interviewed had experienced being discharged once it was felt they were improving slightly. "*Seeing the psychologist is time limited – you get a 6-week block. Then if they say you are a lot better you are signed off and they tell you to come back if you need further help. It then takes 6 months to get back into the system.*" This problem also occurs within other support services and therapies. A parent talked about her adult son's initial positive experience: "*My son is 29 years. Last year was the best year for support. He was had a support worker once a month, gained through a referral from the mental health team.… He tried to go out a bit more (he rarely goes out), started to think about his health and exercise, which he never did and his mental health seemed to be improving a bit. However at the end of the year, because he seemed a bit better, the support was removed and he has gone back into depression.*"
- Being asked to leave general, not autism-specific, groups because they are 'odd' or don't fit in. This is sometimes linked to a lack of information being provided for the person concerned, so that they don't understand the purpose or 'rules' of the group/activity.
- Waiting times are considered too long for adult CMHT and, in particular, CAMHS. One parent talked about how they eventually went private because of long waiting times: "*It took me 13 months to get an appointment with CAMHS. My son could have been dead by them. We had to pay to keep my son alive, so we paid for weekly private sessions which nearly bankrupted us*." Also, once discharged it is difficult to get back in again, as it can take as long as the initial referral.
- People often can't get help from mental health services until they hit a crisis (particularly relevant to CAMHS, in some areas). Mental health services either refused to help or actually say they can't unless the individual is in crisis (e.g. self-harming, attempted rather than threatened, suicide). A number of parents interviewed cited this as a major issue with CAMHS. One parent reported being told: "*CAMHS said they wouldn't do anything until she actually did self-harm."* Another said "*Unless his mental health was severe to point of fatal, CAMHS would not help because they are under-resourced. There needs to be something in place to prevent people getting to crisis point.*"
- Police reacting inappropriately when dealing with people with autism, especially if at crisis point.
- Lack of information about what to expect from mental health services or therapies for the person concerned. Being referred to mental health services of any kind can be a very scary and anxious time for people with autism. One adult talked about this when interviewed: "*I wouldn't go to mental health services as I'm scared of them, I think they'll lock me up.*" Another was referred to a therapy group but was not given sufficient information in advance: "*There was a worry workshop – I had to wait until less than one week before to get full details and confirmation that I had a place. That was worrying!*"

Results from professionals’ focus group

A focus group was held in Eastleigh for a group of professionals from across a variety of mental health and autism-related services, for adults and children, attended by:

- Member of Royal College of General Practitioners’ Autism Steering Group
- Consultant Paediatrician – special interest Neurodisability and Autism, Child Health, Royal Hampshire County Hospital
- Autism Lead, Hampshire County Council Children’s Services
- Clinical Psychologist, CAMHS
- Commissioning Manager – Mental Health West Hampshire Clinical Commissioning Group
- Consultant Clinical Psychologist, Autism Diagnostic Research Centre
- Head of Mental Health and Substance Misuse Services, Hampshire County Council
- Healthwatch Hampshire Engagement and Project Officer
- Healthwatch Hampshire Delivery Manager, Citizens Advice Hampshire
- Healthwatch Hampshire Communications Officer and Senior Administrator
- Choices Advocacy/Hampshire Advocacy Regional Group
- Autism Hampshire

Volunteers from Hampshire Autism Voice and South Hampshire Branch, The National Autistic Society, also attended.

Previous consultation

Attendees were shown the film created for the 2016 consultation on access to GP, Dentist and A&E by people with autism. Results from this consultation can be found on the Autism Hampshire website. From this consultation it became apparent that mental health problems needed to be the focus of the next Healthwatch Hampshire sponsored consultation.

After the showing of the film, a general group discussion raised some specific points:

- People with autism are very misunderstood.
- General feeling from people is that they don’t know how long they’re going to wait, the anxiety becomes overwhelming and meltdown ensues. Anxieties are real but often hidden behind big personalities.
- Understanding is the key – all people involved should have an understanding, professionals and the person with autism themselves. More training is needed for people with autism.
- Sometimes an expectation of mental health services is that it is clinical and hospital like, but it is usually just a normal room and comes as a pleasant surprise. How is a person informed of this ahead of appointments?
- Professionals have a dangerous tendency to tell an autistic person how they think. Too general – whereas with specific support, it should be about how they can support themselves.

Autism and mental health consultation discussion points

The initial findings of the Autism and mental health consultation were presented and discussed in small groups. Key points from group discussions included:

General

- It must be remembered that autism is a hidden disability.

Services

- Commissioning – need to get that right. Autism needs to be considered when commissioning services. Autism professionals need to be involved; in particular, HCC autism leads.
- Preventative measures need to be in place to help those who don’t quite meet the criteria for Advocacy and CAMHS services, to prevent crisis.
- Person-centred approach – not all people with autism are the same. Personalised services are needed as not all issues are due to autism; other factors should be considered. This and better autism awareness in society in general will lead to a decrease in demand for mental health services from people with autism.
- Adapt services to help meet needs of autism – people with autism have processing difficulties, for example, need to find other means of communication besides telephones.
- Be more accepting and positive about autism – it’s not bad, it’s just different.
- When there is a dual diagnosis, autism should be considered as the primary condition.
- ASD often blamed for the symptoms, not looking for other conditions because they are not considered, but could be masked. Hard to define if help needed is for mental health or autism – tricky situation –need time to investigate to find out the best support.
- Public Health should look at morbidity due to different cultures – with strong extended families, providing structure.
- Should children’s/young people’s autism diagnosis be done by CAMHS? Develop more community-based services, with a remit for autism diagnosis.

- Environmental factors – making it user-friendly for people with autism. There are ways all services can publish their information differently, to be more accessible and informative.

Communication and appointments

- People with autism need to think things through before responding due to the time taken to process information.
- Double appointments should be offered, especially for depression – people mustn't feel rushed.
- Appointments should ideally be at the beginning of the day.
- Flag/alert on patient records so receptionists/booking clerks know person has ASD.
- Sharing information between professionals, for example, 10 minute webcast or Skype. There has been used in consultations between Isle of Wight and Hampshire services. A good way to get parties linked up to get the best solutions for a person. Also video consultations could be adopted by many services.

Autism Awareness Training

- Staff Champion, for example, senior receptionist to cascade to other staff. Make use of Autism Ambassador Scheme.
- Should be included as part of initial professional training.
- Ongoing continuing professional development – perhaps include legitimately as part of safeguarding training?
- Autism is not just a male condition. Girls with autism get hidden, sometimes until old age when it's diagnosed as dementia. They become abused and vulnerable.
- When the environment is right, the presentation is different. Misdiagnosis, for example, of dementia. Mimics other conditions.
- Improve early education and access to services.
- Difficult for professional staff to know what is the right thing to do in every case. People fall between the gaps in services. From the consultation results, develop autism best practice guidance for professionals.

Post-diagnosis support

- Personalised, 'strength-based' approach, enabling rather than care and support. Teaching people how to make their own solutions.
- Information regarding condition.
- Case worker/mentor to guide.
- Access to peer support.
- Teach/train people with autism to manage their anxiety.
- Set up, then evaluate after a year, using patient recorded outcome measures.

Transitions

- Transition is a major issue. Currently it is too generalised. It's a massive opportunity to catch people – child to adult, and get the right solutions in place. For example, post diagnosis, transfer from children's to adult services, including mental health.

CBT/italk

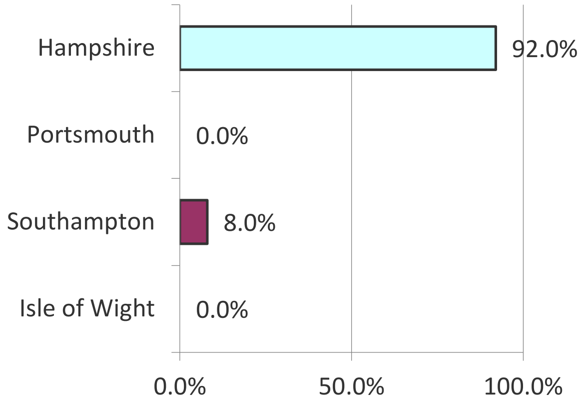
- Italk, as a telephone based service, is not always ideal for people with autism.
- A face-to-face commissioned service is available but unclear how to access this, and unclear if italk know about this service and refer into it.

Results from online survey

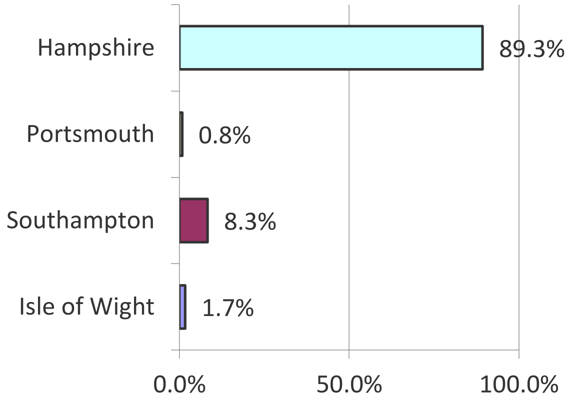
A survey of 32 questions was circulated, from 14 October 2016 to 21 November 2016 via Survey Monkey web link, relating to autism and mental health in Hampshire. A total of 121 responses were received from parents, carers and professionals, and 25 were received from children and adults with autism.

1. Which local authority area do you live in?

ASD participant responses, Answered: 25 Skipped: 0

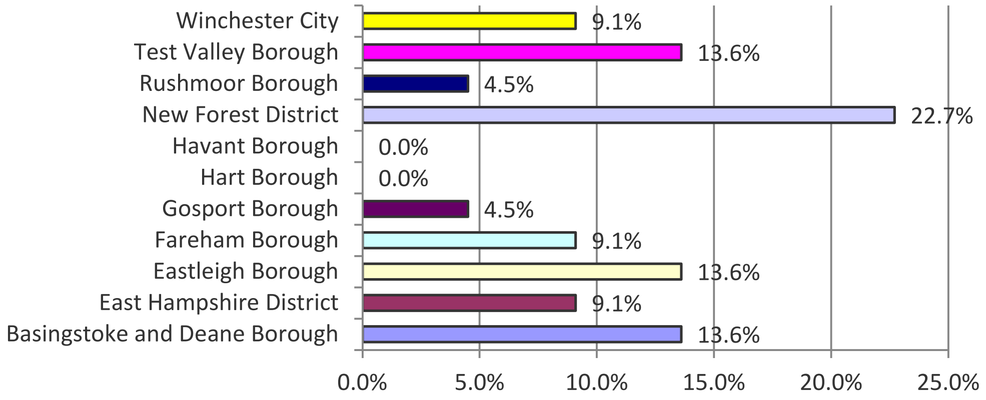


Parent/Carer responses, Answered: 121 Skipped: 0

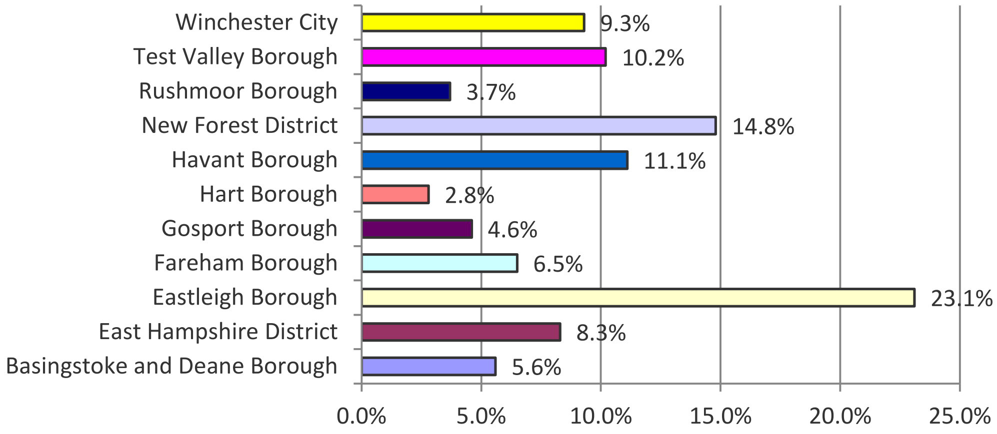


2. If you have answered Hampshire to question 1, which Districts/Boroughs do you live in? If not Hampshire please go to the next question

ASD participant responses, Answered: 22 Skipped: 3

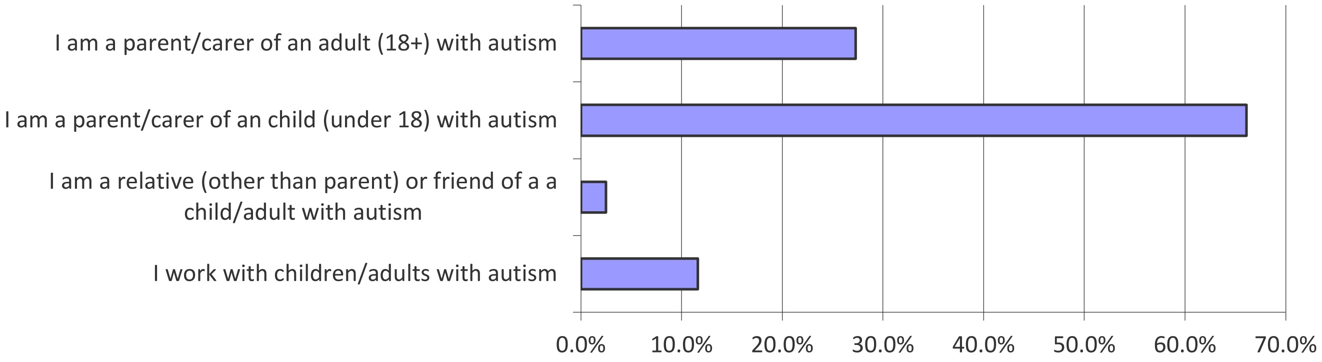


Parent/Carer responses, Answered: 108 Skipped: 13



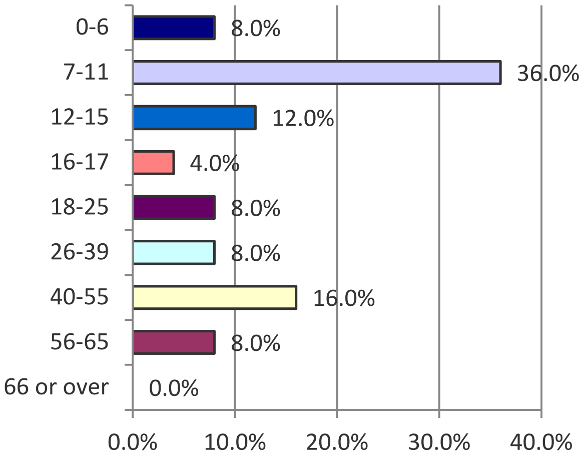
3. What is your relationship with autism?

Parent/Carer responses only, Answered: 121 Skipped: 0

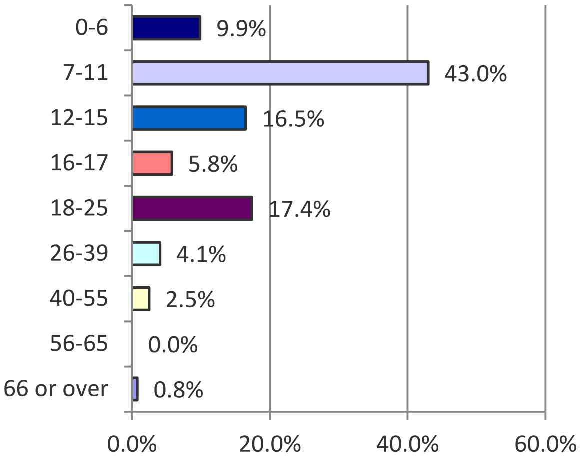


4. Age range of ASD participants

ASD participant responses, Answered: 25 Skipped: 0

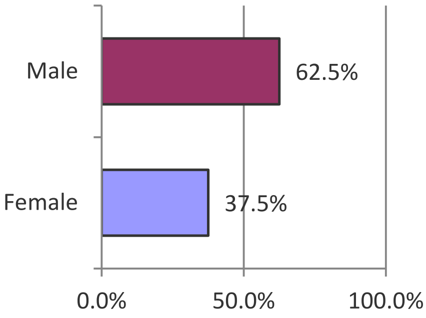


Parent/Carer responses, Answered: 121 Skipped: 0

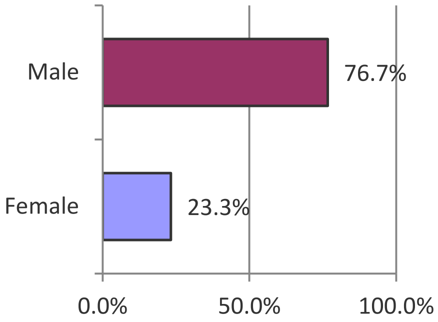


5. Gender of ASD participants

ASD participant responses, Answered: 24 Skipped: 1

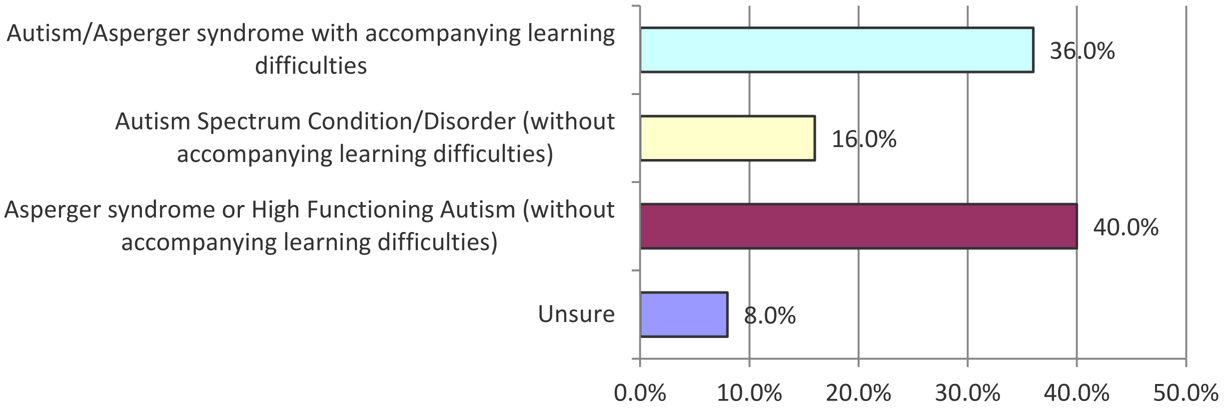


Parent/Carer responses, Answered: 120 Skipped: 1

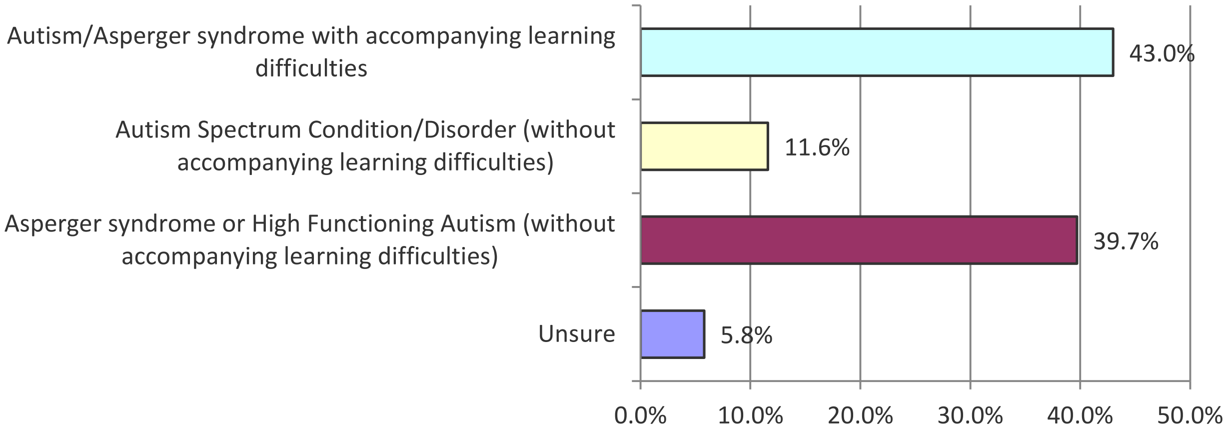


6. How would you best describe the level of autism?

ASD participant responses, Answered: 25 Skipped: 0



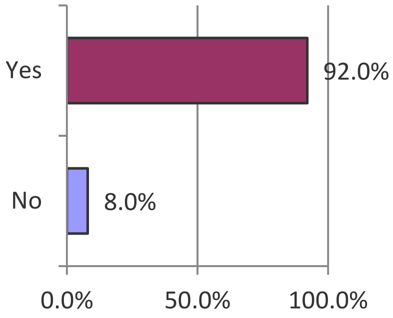
Parent/Carer responses, Answered: 121 Skipped: 0



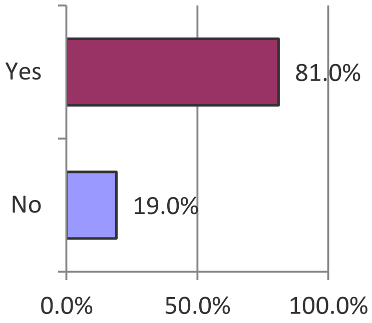
See appendices for all responses.

7. Do you/does your person have a formal diagnosis of autism/Asperger syndrome?

ASD participant responses, Answered: 25 Skipped: 0

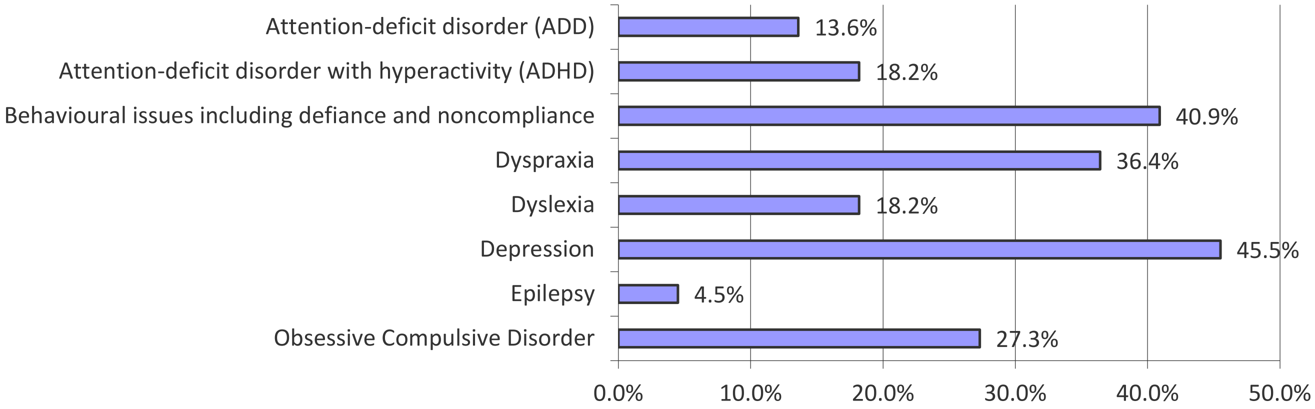


Parent/Carer responses, Answered: 120 Skipped: 1

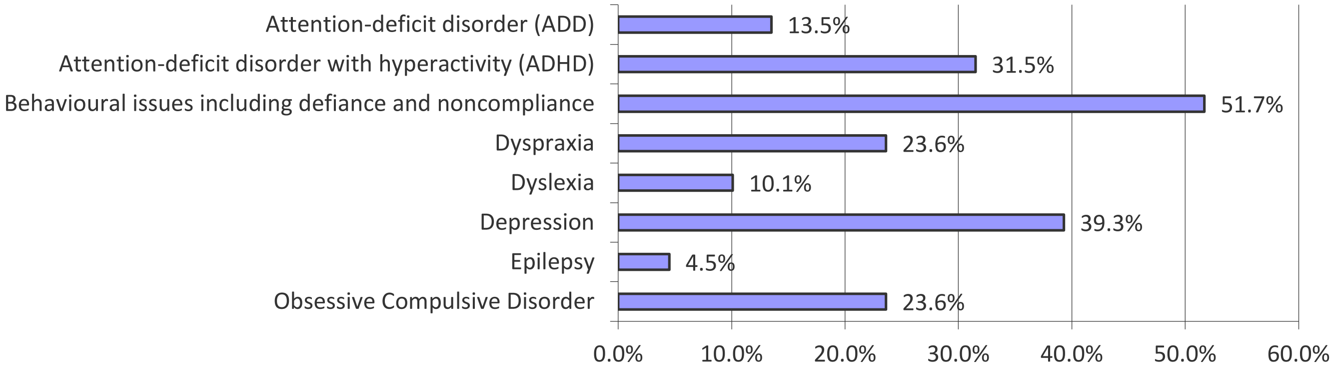


8. Do you/your person have any of the following conditions? (please tick all that apply)?

ASD participant responses, Answered: 22 Skipped: 3



Parent/Carer responses, Answered: 89 Skipped: 32



The most common additional condition for both groups was behavioural issues including defiance and noncompliance (40.9% of ASD, 51.7% of parent/carers). The second most common was depression at 45.5% of ASD respondents and 39.3% of parent/carer responses. Other conditions listed in the comments included anxiety (5 ASD responses, 17 parent/carer responses), and sensory processing disorder (2 ASD responses, 10 parent/carer responses).

See appendices for all responses

9. What does good mental health mean to you? What do you consider to be a mental health issue?

ASD participant responses, Answered: 19 Skipped: 6 *Parent/Carer responses, Answered: 103 Skipped: 18*

Open-ended question. Many ASD respondents equate good mental health with being happy, being able to function in society and being normal. One simply stated *"security"*, and another felt that good mental health was about *"feeling good about myself. Having some friends and feeling happy. Not hurting myself and others."*

Good mental health means:

- able to access work
- able to access social activities
- feeling good about myself
- feeling happy
- having friends
- not hurting myself and others
- no anxiety
- feeling secure
- understanding people
- being normal
- rational, age-appropriate behaviour
- logical thinking

A mental health issue is:

- anxiety
- psychological imbalance
- depression
- Obsessive Compulsive Disorder
- Anxiety
- not coping with changes to routine
- overwhelming fear
- overwhelming stress

The parent/carer responses are very similar, with many stating that an ability to cope is key to good mental health. Anxiety is frequently mentioned and viewed as a mental health issue, as is depression. One person stated that a mental health issue is anything that disrupts a person's *"emotional wellbeing"*. Another response was that good mental health is *"being able to manage the ups and downs life throws at us - emotionally and physically - without suffering severe difficulties in managing one's own emotions and behaviours."* The recurring responses are listed as follows:

Good mental health means:

- being happy, content, balanced and fulfilled
- feeling capable
- feeling in control
- feeling calm
- feeling secure
- feeling supported and safe
- emotional resilience
- understanding issues and challenges and being able to deal with them
- self-awareness
- ability to self-regulate
- having meaningful relationships
- positive outlook on life, being able to plan and achieve
- rational, age-appropriate behaviour
- logical thinking

A mental health issue is:

- anxiety
- mood swings
- depression
- Social Communication Disorder
- Obsessive Compulsion Disorder
- bipolar
- schizophrenia
- paranoia
- self-harm
- eating disorders
- anything other than 'normal'
- inability to self-regulate
- low self esteem
- not fitting into society/social isolation
- not coping with changes to routine
- overwhelming fear
- overwhelming stress

See appendices for all responses.

10. What does "mental health services" mean to you?

ASD participant responses, Answered: 19 Skipped: 6 *Parent/Carer responses, Answered: 107 Skipped: 14*

Open –ended question. Most of the ASD respondents said that mental health services means *"help"* – help to identify issues, gain skills, and to be able to live happily. Some also gave a literal description of NHS qualified professionals. Two mentioned that services should understand not just mental health but autism too.

Mental health services mean (ASD response):

- Experts in autism and associated mental health conditions
- NHS qualified professionals
- support/advice when in crisis
- help to identify issues
- help to gain good mental health
- help to gain skills
- support holistic care
- removing barriers to needs
- able to deal with BOTH the autism and the mental health difficulties
- medication

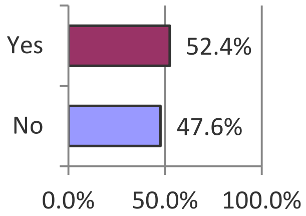
Mental health services mean (parent/carer response):

- professional help
- support no matter what the autism diagnosis
- support for all - patients and family/carers
- a service that listens to parents
- accessible - NHS not private
- available
- therapy/treatment
- advice
- CAMHS

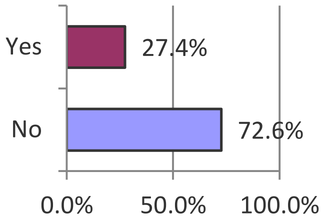
See appendices for all responses.

11. Would you/your person be able to recognise if they have a mental health problem?

ASD participant responses, Answered: 21 Skipped: 4



Parent/Carer responses, Answered: 117 Skipped: 4

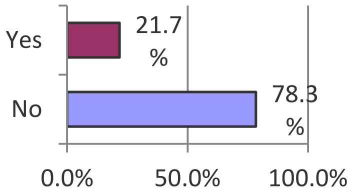


The parents/carers report a range of experiences in their comments. Some can recognise it and realise they need help, some can recognise it and not realise the impact of it on themselves, some realise they feel different but don't recognise it as a metal health problem. Some cannot recognise it as to them being in a constant state of anxiety is normal. Some need it to be pointed out to them.

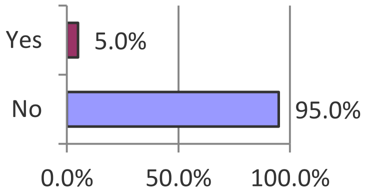
See appendices for all responses

12. Would you/they be able to seek help independently if they have a mental health problem?

ASD participant responses, Answered: 23 Skipped: 2



Parent/Carer responses, Answered: 119 Skipped: 2



Of the ASD respondents, one said that they weren't always able to seek help as *"I don't (always) realise severity of my condition"*. Another said that *"it was very difficult and I had to write to my GP as I couldn't verbalise it"*. Of the parent/carers responses, many of the people they were responding about were too young to seek help for themselves. Those who were old enough had a range of barriers holding them back from seeking help:

- wouldn't know where to begin
- rarely get moments of clarity
- caught up in own world
- anxiety prevents interactions
- ability varies on a daily basis
- to them it's normal
- not enough patience to go through the system
- selective mute
- cannot communicate well enough

Only one person responded yes, their person can seek help independently.

See appendices for all responses.

13. What has been the impact of mental health problems on you/your person's life?

ASD Participant responses, Answered: 25 Skipped: 0

Answer options	**Strongly agree**	**Agree**	**Neither agree or disagree**	**Disagree**	**Strongly disagree**	**N/A**
I avoided going to school/work	45.8%	20.8%	16.7%	8.3%	8.3%	0.0%
I found it difficult to find employment	31.8%	9.1%	13.6%	4.5%	0.0%	40.9%
I avoided going out/social situations	62.5%	33.3%	0.0%	0.0%	0.0%	4.2%
I found it difficult to maintain relationships with friends and partners	41.7%	33.3%	8.3%	0.0%	0.0%	16.7%
I found it difficult to maintain relationships with family members	34.8%	39.1%	13.0%	4.3%	4.3%	4.3%
My physical health declined	27.3%	54.5%	9.1%	9.1%	0.0%	0.0%
I displayed challenging behaviour	54.2%	33.3%	8.3%	4.2%	0.0%	0.0%

Parent/Carer responses, Answered: 121 Skipped: 0

Answer options	**Strongly agree**	**Agree**	**Neither agree or disagree**	**Disagree**	**Strongly disagree**	**N/A**
Avoided going to school/work	47.5%	25.0%	10.0%	9.2%	7.5%	0.8%
Found it difficult to find employment	18.1%	1.7%	2.6%	3.4%	0.0%	74.1%
Avoided going out/social situations	53.8%	31.1%	5.0%	5.0%	1.7%	3.4%
Found it difficult to maintain relationships with friends and partners	60.8%	26.7%	8.3%	2.5%	0.0%	1.7%
Found it difficult to maintain relationships with family members	34.7%	30.6%	13.2%	14.0%	5.8%	1.7%
Physical health declined	25.0%	25.8%	18.3%	15.8%	10.0%	5.0%
Displayed challenging behaviour	63.9%	22.7%	6.7%	3.4%	2.5%	0.8%

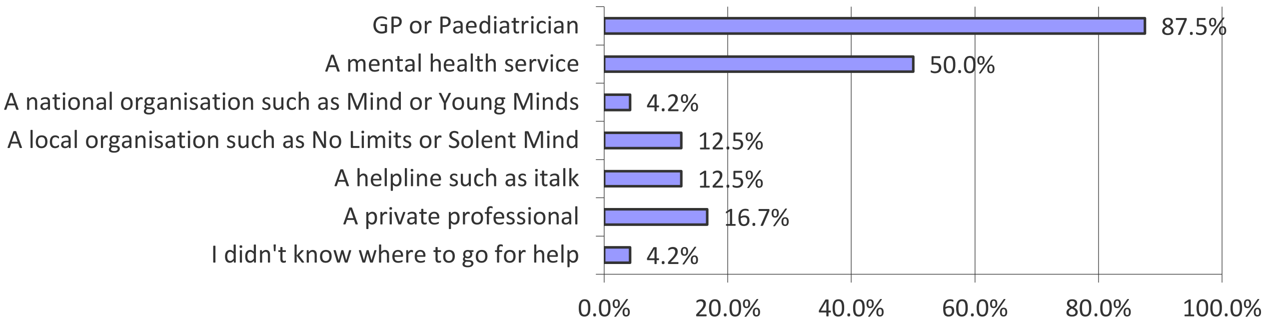
One ASD respondent said that they felt persecuted by the DWP and finances have been severely affected, another had to *"cover up my autism and my bad anxiety"* and another had *"social services involvement because of having children that would have been affected if I'd been successful in suicide attempts"*. Other answers given by parent/carers were:

- low self-esteem
- self-harm and self-neglect
- nightmares, physical symptoms
- went to prison
- eating disorder
- dropped out of college

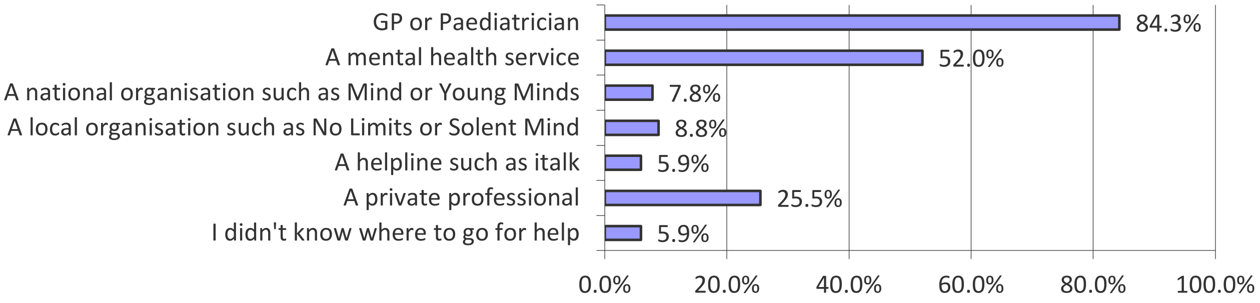
See appendices for all responses.

14. In the last 3 years where did you/your person first go to get help? Tick all that apply.

ASD participant responses, Answered: 24 Skipped: 1



Parent/Carer responses, Answered: 102 Skipped: 19

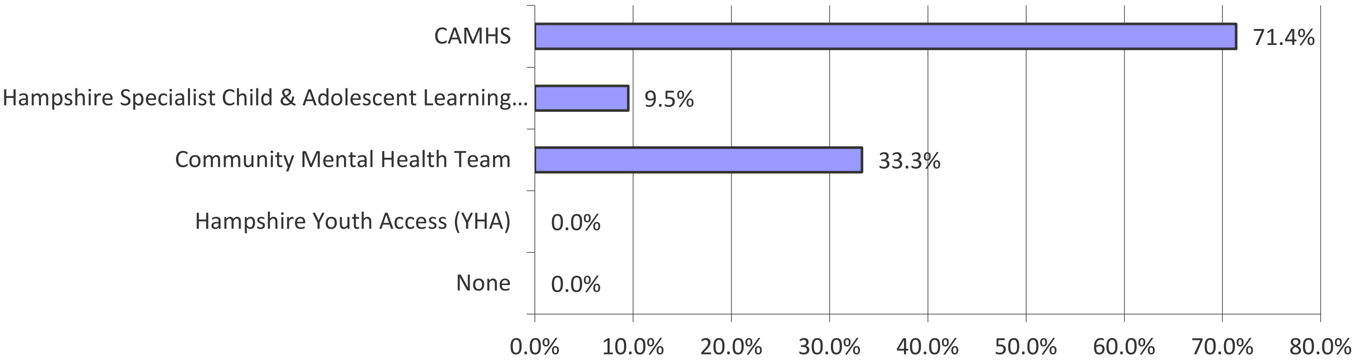


Of the ASD respondents, one paid for private counselling and one went to a speech and language service. The most common services that Parent/Carers went to for help were school, internet/social media groups and the National Autistic Society.

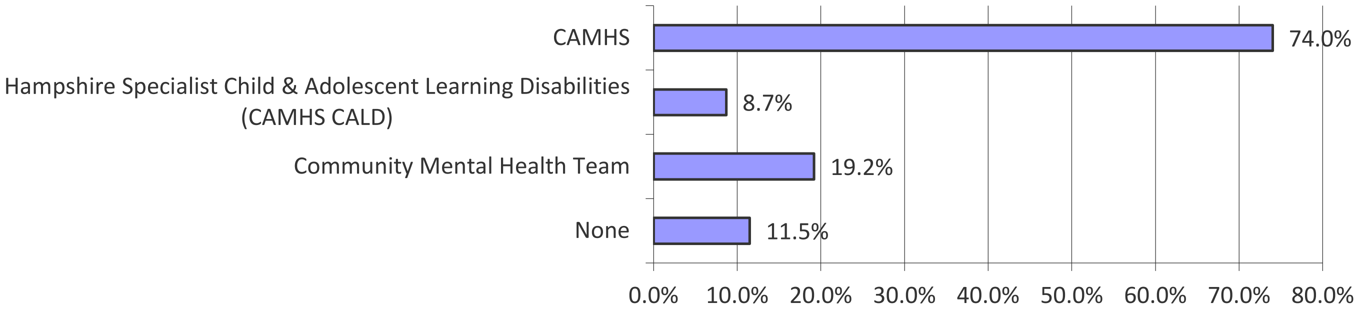
See appendices for all responses.

15. In the last 3 years, what services has you/your person accessed or tried to access? Tick all that apply.

ASD participant responses, Answered: 21 Skipped: 4



Parent/Carer responses, Answered: 104 Skipped: 17



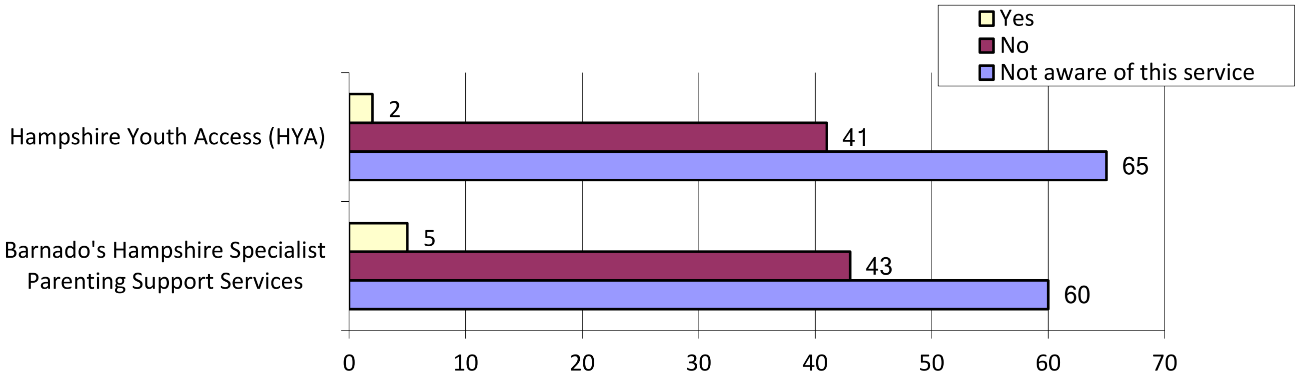
Of the ASD respondents, one used an incontinence service and one used the charity Enham Trust. The parent/carers used the following services:

- Individual specialist (e.g. psychologist, SALT, OT)
- Fareham Mind
- Maple Ridge Outreach (specialist school)
- Social services Learning Disability team
- Eastleigh Youth Counselling Services
- Children with Disabilities team (Social Care)
- Mustard Seed Autism Trust
- Portage
- Sleep clinic
- Early Intervention Psychosis Team

See appendices for all responses.

16. Have you accessed the following services?

Parent/Carer responses only, Answered: 109 Skipped: 12



17. Please rate how easy it was to get help for your/your person's mental health problems?

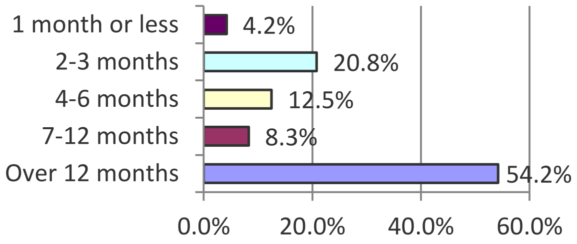
Answer options	Very easy	Easy	Neither easy nor difficult	Difficult	Very difficult
ASD participant responses, Answered: 24 Skipped: 1	0.0%	7.1%	7.1%	24.7%	46.0%
Parent/Carer responses, Answered: 104 Skipped: 17	0.0%	3.6%	7.2%	30.8%	54.3%

Of the ASD respondents who commented, one said that *"even after attempted suicide (I) did not meet the criteria"*, another said that *"my GP initially referred me to italk. This is not very practical for someone who doesn't like speaking to strangers on the phone"*. The responses from the parent/carers were all negative, with failure to access CAMHS a very common problem. Some had multiple referrals before being seen. Most were told by their GP or by CAMHS itself that they could not be treated for mental health issues because they had autism. Professionals are not able to connect or treat the two conditions together. One person's GP added OCD to a referral letter just so that the person would be accepted by CAMHS.

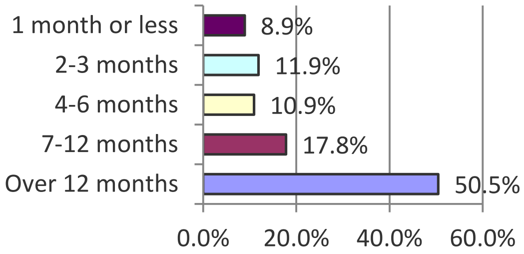
See appendices for all responses.

18. How long did it take to get help for your person's mental health problems?

ASD participant responses, Answered: 24 Skipped: 1



Parent/Carer responses, Answered: 101 Skipped: 20

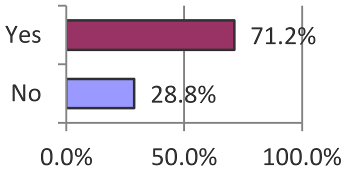


Of the comments received from parents/carers, 9 said that they received no help, 8 were still waiting, 4 have waited over 3 years, and one person over 5 years. Three of the respondents paid for private therapy.

See appendices for all responses.

19. Were you able to attend mental health services appointments with your person with autism?

Parent/Carer responses only, Answered: 104 Skipped: 17



20. How far do you agree with the following statements: When you saw a mental health professional....?

ASD participant responses, Answered: 22 Skipped: 3

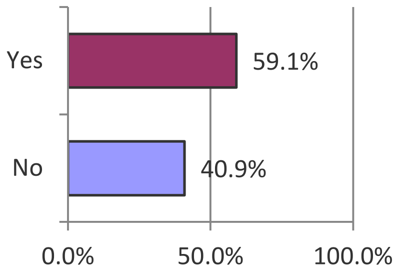
Answer options	**Strongly agree**	**Agree**	**Neither agree or disagree**	**Disagree**	**Strongly agree**
Did the person or people you saw listen carefully to you?	12.2%	40.6%	8.1%	24.4%	4.1%
Did the person or people you saw understand how your mental health needs affect other areas of your life, such as school, work and relationships?	7.9%	19.9%	11.9%	43.7%	4.0%
Did the person or people you saw understand what is important in your life?	7.9%	11.8%	11.8%	51.3%	3.9%
Did the person or people you saw help you with what is important to you?	3.9%	7.8%	11.7%	58.6%	3.9%
Did the person or people you saw help you feel hopeful about the things that are important to you?	0.0%	11.7%	15.6%	50.7%	7.8%
Were you involved as much as you wanted to be in agreeing what care you received?	0.0%	7.8%	19.5%	54.6%	3.9%

Parent/Carer responses, Answered: 82 Skipped: 39

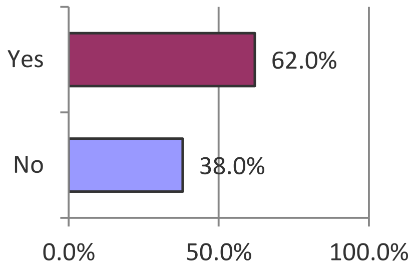
Answer Options	**Strongly agree**	**Agree**	**Neither agree or disagree**	**Disagree**	**Strongly disagree**
Did the person or people you saw listen carefully to you and your person with autism?	32.9%	34.1%	13.4%	17.1%	2.4%
Did the person or people you saw understand how your person's mental health needs affect other areas of their life, such as school, work and relationships?	26.8%	26.8%	17.1%	24.4%	4.7%
Did the person or people you saw understand what is important to your person with autism in their life?	19.5%	29.3%	18.3%	28.0%	4.7%
Did the person or people you saw help your person with what is important to them?	10.0%	21.3%	28.8%	31.3%	8.4%
Did the person or people you saw help your person feel hopeful about the things that are important to them?	6.1%	19.5%	35.4%	31.7%	7.0%
Were you involved as much as you wanted to be in agreeing what care your person received?	15.0%	25.0%	21.3%	31.3%	7.2%

21. Did the person or people you saw put your/your person’s problems down to your/their autism?

ASD participant responses, Answered: 22 Skipped: 3



Parent/Carer responses, Answered: 79 Skipped: 42

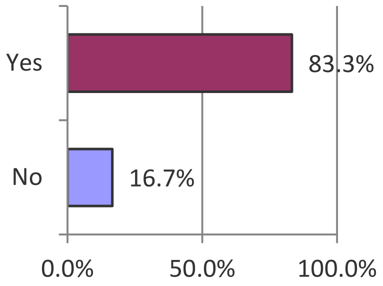


There were not many comments from the ASD respondents, but one said that *“they admitted to not understanding autism, and said they might be able to learn from my case”*, and another that *“they didn’t know how I could have autism because I ‘could speak’ so I had to explain to her”*. Some of the parent/carers highlighted that the professionals they had seen had not understood autism, and if they did would admit that *“it’s not our field”*.

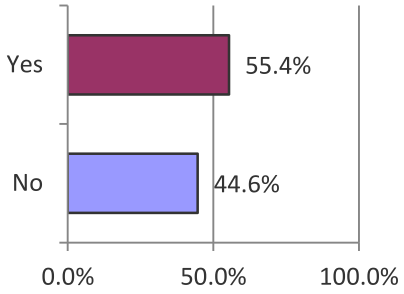
See appendices for all responses.

22. Did you feel that you/they did not receive appropriate treatment because of this?

ASD participant responses, Answered: 18 Skipped: 7



Parent/Carer responses, Answered: 65 Skipped: 56

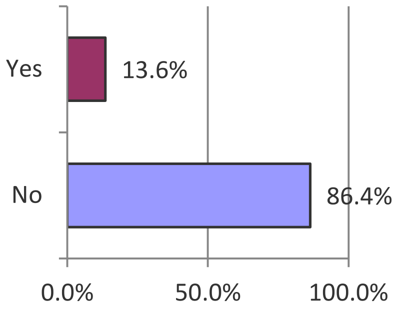


Some of the parent/carers felt that their person’s mental health problems had been dismissed because of their autism diagnosis. One commented that the person that they saw said *“that’s just the ASD, we can only see patients with conditions that can be treated. Autism can’t be treated, you have to manage”*. Another commented that *“we received the appropriate treatment for the acute phase of his illness but there was a huge lack of knowledge and expertise about autism which I think hampered things and did make us feel unsupported at times”*.

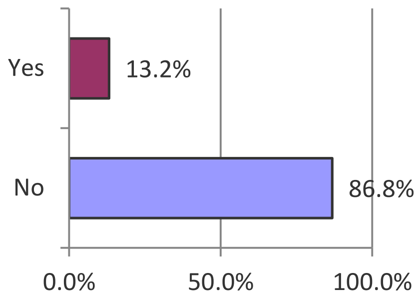
See appendices for all responses.

23. In the last 3 years, do you feel your person has accessed mental health services often enough for their needs?

ASD participant responses, Answered: 22 Skipped: 3



Parent/Carer responses, Answered: 106 Skipped: 15



See appendices for all responses.

24. How has caring for your person with autism affected you and your family? Has it led to health problems, mental or physical?

Parent/Carer responses only, Answered: 93 Skipped: 28

Open-ended question to parent/carers only. While three respondents said they have been able to cope so far and report no impact and one person commented that *"we have devised coping strategies ourselves to make our family stronger"*, the majority of the comments outline a negative impact on family life. This can be summarised as follows:

- marital problems - separation, arguments
- depression
- stress, increased anxiety
- restricted activities
- exhausted due to lack of sleep, run down
- gave up work/unable to work due to caring for person
- siblings feel responsible, leading to stress
- one person reported taking medication to cope
- loneliness due to social isolation
- violence towards family
- developed fibromyalgia
- existing physical conditions worsened

A common theme in the comments is that living with a person with mental health problems and autism is *"mentally draining and physically demanding"*, and it has *"taken over our lives"*.

See appendices for all responses.

25. What are your main concerns going into the future for your person with autism?

Parent/Carer responses only, Answered: 93 Skipped: 28

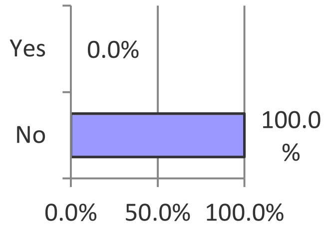
Open-ended question for parent/carers only. The overriding concern for the future is 'what will happen to my person when I am gone?' Other topics that concern parent/carers about the future of their person are:

- lack of support, awareness, individual services
- lack of self-esteem and confidence
- deterioration of person due to lack of support
- fear of a major incident/person going to prison
- exploitation/being bullied
- living a normal life
- coping at school (especially secondary)
- getting work
- coping at work
- living independently
- communicating needs
- keeping safe and controlling aggression
- making friends

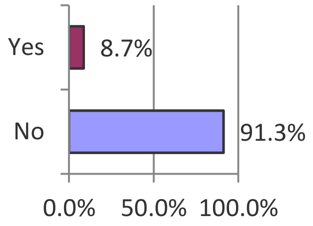
See appendices for all responses.

26. In the last 3 years, have you/your person transitioned from child mental health services to adult mental health services?

ASD participant responses, Answered: 20 Skipped: 5



Parent/Carer responses, Answered: 92 Skipped: 29



27. Please outline your experience of the transition, specifically access to mental health services during transition and care received post transition.

ASD participant responses, Answered: 2 Skipped: 23 *Parent/Carer responses, Answered: 27 Skipped: 94*

Open-ended question. Of the 27 parent/carers who answered this question, 11 said that they had had no transition. Of those who did go through the transition, only one person said it went well. Another said that it was *"absolutely disastrous"*, another that they did not receive any services after transition, and another said they had a transition meeting, was discharged, then they *"had to wait for crisis before beginning a new referral and start at the bottom of the waiting list again."*

See appendices for all responses.

28. How far do you agree with the following statements? Since accessing mental health services in the last 3 years.....

ASD participant responses, Answered: 23 Skipped: 2

Answer options	**Strongly agree**	**Agree**	**Neither agree or disagree**	**Disagree**	**Strongly disagree**
You are more content in your life	0.0%	15.0%	30.1%	15.0%	26.3%
Your family is functioning better	3.9%	7.8%	27.2%	15.5%	31.1%
There are significant improvements in your educational or career achievement	0.0%	7.7%	27.1%	23.2%	27.1%
There are significant improvements in your social relationships	3.8%	3.8%	15.3%	19.2%	42.2%
There are significant improvements in your physical health	0.0%	7.7%	23.2%	31.0%	23.2%

Parent/Carer responses, Answered: 82 Skipped: 39

Answer options	**Strongly agree**	**Agree**	**Neither agree or disagree**	**Disagree**	**Strongly disagree**
Your person with autism is more content in their life	1.0%	15.7%	18.7%	29.5%	31.4%
Your family is functioning better	0.0%	14.9%	26.8%	21.8%	32.8%
There are significant improvements in your person's educational or career achievement	2.0%	13.8%	21.6%	24.6%	34.4%
There are significant improvements in your person's social relationships	2.0%	7.8%	23.5%	24.5%	38.3%
There are significant improvements in your person's physical health	1.0%	8.9%	40.3%	18.7%	27.5%

One ASD respondent commented that *"I am not trying to kill myself anymore"*. Of the parent/carer respondents, some commented that their person has improved but not because of accessing mental health services. Improvements have been due to:

- not attending school full time
- excellent support from school
- removal of stress caused by CAMHS
- parents supporting through their own research
- involvement of the Reablement team

Two respondents commented that improvements have been due to accessing mental health services, one by accessing medication and CBT, the other by giving their person a *"better understanding of how anxiety affects him on a daily basis"*.

See appendices for all responses.

29. In the last 3 years, what went well when using mental health services?

ASD participant responses, Answered: 16 Skipped: 9 *Parent/Carer responses, Answered: 77 Skipped: 44*

Open-ended question. 7 of the 16 ASD respondents who answered this question said that nothing went well. One person commented that *"leaving and going private"* worked for them. What did go well was:

- speed of being seen was good
- attended a Mind well-being clinic
- access to material and knowledge regarding condition
- getting/changing medication

Of the parent/carer respondents, 20 answered that *"nothing"* went well when using mental health services. There were several positive experiences however. What did go well was:

- communication
- consistent approach with same consultant
- went private
- received a diagnosis leading to better support at school
- compassionate/helpful staff
- received EMDR treatment
- person had someone to talk to
- received social communication sessions
- speed of initial referral
- received good advice
- received practical strategies session

One respondent commented that *"everyone we met was compassionate, honest and kind. We've had great support"*, and another that their person *"has gained a better understanding of how they fit into society and what they need to be able to cope well with school life"*. However, one respondent noted that *"they never had the appointments regularly enough and the staff turnover was high meaning no regular psychologist to build a relationship with"*.

See appendices for all responses.

30. What are your ideas of how mental health services and access to them can be improved?

ASD participant responses, Answered: 18 Skipped: 7 *Parent/Carer responses, Answered: 89 Skipped: 32*

Open –ended question. Both groups of respondents gave a range of suggestions that overlapped, therefore they are listed here together:

- employ more people
- more funding made available
- shorter waiting times
- make more services available
- understanding that an autism diagnosis does not preclude someone from being able to benefit from mental health services
- understanding of the impact upon the family/family support
- better autism training for staff
- continuity of help, better monitoring
- efficient handover/transitions
- listen to parents (rather than blame them)
- support upon diagnosis
- better flexibility in how to communicate with people with ASD e.g. using text or email when talking by phone is difficult
- joint working between autism and mental health teams
- specialist Asperger training for LD support teams
- 24/7 access
- drop in clinics
- easier access to services
- better information about services that are available
- automatic transition from child to adult mental health services
- a service that is available in schools
- better child specific therapies
- more home visits
- earlier intervention - help before crisis reached
- quicker response to crisis
- create a clearly defined autism pathway within mental health services
- specialist autistic mental health team
- social stories made available

See appendices for all responses.

31. Please rate your overall experience of 'mental health services'…

Answer Options	I had a very poor experience	I had a poor experience	My experience was neither poor nor good	I had a good experience	I had a very good experience
ASD participant responses, Answered: 22 Skipped: 3	41.8%	25.1%	16.7%	8.4%	0.0%
Parent/Carer responses, Answered: 100 Skipped: 21	34.0%	21.0%	32.0%	11.0%	2.0%

Appendices

comments and full responses to open-ended questions

Question 6: How would you best describe the level of autism?

ASD participant responses:

- ASD + specific learning difficulties + anxiety/depression/paranoia + OCD

Parent/Carer responses:

- Partial chromosome deletion and sensory processing dysfunction
- Autism, behavioural emotional and social difficulties and possible PDA
- Primarily ADHD
- Aspergers traits but not full spectrum
- Autistic spectrum condition (PDD) with ADHD
- Dyspraxia with ASD traits, high anxiety
- High functioning ASD with PDA
- Suspected autism ADHD
- And PDA

Question 8: Do you/your person have any of the following conditions? (please tick all that apply)?

ASD participant responses:

- Anxiety + paranoia
- Anxiety
- Nasosomnia (no sense of smell)
- Attachment and anxiety
- Tourette's Syndrome
- Sensory processing disorder
- SPD and anxiety and incontinence
- Generalised anxiety disorder

Parent/Carer responses:

- Downs syndrome
- High Levels of Anxiety & gender issues
- Anxiety and attachment disorder
- Anxiety, speech and language disorder
- SPD
- Mental health - possible personality disorder diagnosis (consultants disagree)
- Gross & Fine Motor Skill Disorder
- Processing delay
- Hypermobility
- Anxiety resulting in school refusal
- Anxiety
- Low muscle tone, possible CP and/or epilepsy
- Sensory processing disorder
- Sensory Processing Difficulties; Anxiety
- Learning difficulties

- Severe speech & language disorder
- Hypermobility
- Anxiety
- Anxiety
- Social Anxiety Disorder, Select Mutism, SPD
- Sensory processing disorder and chromosone deletion
- High Anxiety, general learning difficulties
- Genetic difference - impact unknown, asthma
- SPD
- Sensory processing disorder and partial chromosome deletion
- Severe Anxiety
- Disabled right arm
- Anxiety
- Anxiety
- Sensory processing disorder, hears voices, extreme anxiety.
- Anxiety
- Severe Body Dysmorphia/ Anorexia
- Social anxiety
- Dystonia
- SPD and anxiety and incontinence
- Disabled right arm
- Sensory processing disorder
- PDA
- Agoraphobia
- Sensory Processing Disorder
- PTSD and Complex Anxiety Syndrome
- Born with T.O.F
- PTSD,
- Anxiety

Question 9: What does good mental health mean to you? What do you consider to be a mental health issue?

ASD participant responses:
- Having all the problems (and therefore symptoms) minimised and having reliable, appropriate and enough specialist support to keep threats at bay (such as threats from assessors/persecutors at DWP, council, etc.) and having access to work, financial help etc. supported appropriately and reliably.
- Feeling good about myself. Having some friends and feeling happy. Not hurting myself or others.
- Being able to function on a daily basis and being able to access work and social activities.
- To be able to live within the community peacefully and have no anxiety.
- Psychological imbalance causing distress anxiety and physical ill health which impact on quality of life.
- Ongoing stable psychological equilibrium.
- Good mental health for me would mean being able to cope within the work place, enjoy daily life and feel happier. For me mental health issues I have are: depression, OCD and anxiety.
- Security.
- I don’t know.
- extreme Anxiety affecting daily life.
- Help and support.
- Having days when life is not a trial or seems to bring constant worries all the time.
- To be happy and function like everyone else.
- Able to function on daily basis with minimal help. Understanding the situation and people better. Being aware of taking care of self. Being independent. The absence of all the things described earlier which means being dependent on someone to help you in your daily life I would consider a mental health issue.
- Being happy and able to interact effectively and appropriately in most social situations.
- Good mental health means being normal.
- Being unhappy.
- Delay in getting the right treatment.
- Being able to cope with feelings and thoughts in a balanced way that is not detrimental to basic living.

Parent/Carer responses:
- Able to access help easily.
- Depression.
- Able to live happily.
- Happy, content, balanced, fulfilled. The opposite of the above + Anxiety mood swings, depression.

- Feeling of wellbeing and positive relationships with other people.
- Very small description for an enormous topic. Anything other than 'normal'!
- A happy confident outlook on life and being able to tackle everyday issues. Not being able to process issues as others do, being overwhelmed by daily life.
- Resilience to life's ups and downs, a self-awareness of mood and ability to self regulate. Mental health issue anything where the individuals sense of well-being is seriously disrupted and they are unable self regulate.
- Good mental health is being happy with who you are and feeling good about yourself.
- Happy, confident child. Not a depressed, unsettled, dark thoughts child.
- That's the person has support where and when needed. Leaning to support on bad days.
- Feeling purposeful and having hope for the future. Having meaningful relationships. Mental health issue would be if someone was feeling that there was no purpose in life and no motivation to keep trying.
- Being mentally able to manage day to day life in a state of calmness.
- Being able to manage the ups and down life throws at us - emotionally and physically - without suffering severe difficulties in managing one's own emotions and behaviours.
- Being happily able to cope with life. Being anxious, having very low self-esteem, saying life is terrible.
- Feeling capable of taking on the world.
- Depression, anxieties, autism, Add, OCD, social communication disorder, High Functioning autism, Asperger's Syndrome Severe Autism, Bipolar.
- Being happy with yourself and having the self-esteem to deal with daily life. I consider a mental health issue to be something like anxiety or depression.
- Good mental health means being happy.
- An understanding of the issues that face and ability to identify and deal with them calmly.
- Security.
- Not consistently complaining of low mood. Feeling in control of ones emotions and behaviour most of the time.
- Able to live happily and be content.
- A calm state of mind, able to deal with life's problems.
- Positive. In my son's case, anxiety, worry, depression, paranoia.
- Anything that affects how you think and view yourself within society and how happy or unhappy you are within yourself.
- Good emotional wellbeing able to cope and function well. Mental health issue is anything that disrupts this ability.
- Positive and realistic view of himself in relationship to the world, ability to reach full potential with a sense of wellbeing.
- Being happy.
- Sound mind and able to make appropriate decisions that do not put yourself in danger or harm.
- Able to get on with your life - when things get too much and daily things become difficult.
- Happy, content most of the time, functioning when functioning impaired by mood.
- Ability to think and act for self and be happy in oneself. Ability to be deal with anxiety and the negative impact others may have on you.
- Ability to participate in normal day to day activities and enjoy life.
- Being able to feel content and secure s d function within society.
- Having low levels of anxiety, healthy self-esteem, and generally paitive outlook on life.
- Good mental health is having healthy self-esteem and low anxiety. High levels of anxiety, low self-esteem, depression, and compulsive behaviour are all mental health issues.
- Being unaware of social norms. Not fitting into society. Unable to control emotions. Scared of the world.
- Happy and healthy. Depression, anxiety, schizophrenia. Anything related to the function of the brain.
- I don't believe my son to have a mental health condition but an actual learning difficulty.
- A feeling of being able to cope with everyday life and be able to process the negative aspects and move on.
- Sense of wellbeing, belonging, self-worth and being of value. Anxiety, depression, social isolation, diagnosed MH issue, i.e. Bi-polar, schizophrenia.
- Someone who can cope with every day challenges. Mental health is someone who struggles with coping with life on a daily basis if the routine changes it's a major issue for them.
- Having effective coping mechanisms to deal with everyday life when life is difficult or stressful. Sense of wellbeing. Able to enjoy life.
- Good health = feeling good about yourself, confident. Lots of anxiety, letting others control you, taking drugs to self-medicate and to feel you have 'friends'.
- Advice, knowledgeable support, guidance for family and school to help the young person to have confidence to address their difficulties. Cognitive therapy if appropriate.
- Happy, confident, emotional resilience. Issues: anxiety, depression, low self-esteem, mood swings.
- Good health = being happy with yourself & be able to cope with everyday things in life.
- Ability to cope with day to day life and work.
- The ability to function without being limited by anxiety, depression...
- Good mental health means that you are reasonably settled in your life and are able to make rational decisions around safety. A mental health issue is anything that compromises this and causes depression, low self-esteem and worth and self harm.
- To be able to make logical choices. To seek happiness and not harm. Our son has had extensive early trauma prior to us adopting him, on top of Aspergers. Trauma continues to impact on his mental wellbeing.
- Good mental health is functioning at a comfortable even level. A mental health issues is when that balance cannot be maintained with support from family GP, etc.

- Being happy with normal ups and downs and manageable anxiety.
- Ability to function and enjoy life and to cope with what life throws at you. Mental health issues such as anxiety and depression become serious when an individual can't function as they usually do.
- Good MH means feeling happy with life and being able to contribute to society.
- Good mental health is being able to act like a rational, typical adult/person. Mental health issues such as anger issues, lack of capability to act adult-like in an adult situation, acting like a mature adult around younger people, rational behaviour.
- Help and therapy not just offered medication.
- Feel good about self. Anything that has a negative impact on a person life and social experiences.
- Ability to focus on tasks. To make own decisions, To manage one's own life. Anxiety, Depression, Self Harm
- Anxiety and depression are mental health issues.
- Learning to cope with life from within.
- Feeling able to function in everyday life.
- Good mental health means to me that the person has the emotional, social and cognitive capacity to be able to successfully function in every aspect of society and therefore a mental health issue would be any issue which impacts on this ability.
- Someone content, stable, engaging, confidence, Self harming, high anxiety, low self-esteem/confidence, depression, social isolation.
- Ability to look forward, plan, achieve and enjoy. Any mental health change which impacts on the ability to achieve the above.
- To be able to cope with, manage the day to day issues that occur over a lifetime. Being unable to cope or a significant incident can lead to mental health. In children it is much more complex.
- Being able to cope with life in general, mental health you can't cope with even the smallest of things.
- Being a mental state which allows you to function in daily life.
- Happy person.
- Happy and safe well-being.
- Being able to achieve a reasonable quality of life most of the time.
- Good mental health is an ability to enjoy and participate in family life, emotional resilience and manageable emotions. Mental health issues include anxiety depression obsessive compulsive disorder and symptoms which impair daily life and reduce enjoyment and participation.
- Good mental health means an ability to enjoy life and participate in activities and socialise, good level of self-esteem and emotional resilience. Mental health issues include anxiety, persistent low mood and depression, inability to participate in social activities due to fear or paranoid thoughts, obsessions which restrict enjoyment in life, panic attacks, agoraphobia, suicidal thoughts and explosive episodes of anger which a person cannot control.
- Excessive anxiety/worry. Long low mood and suicidal views. Good mental health to me is to be able to rationalise situations without a negative escalation. To be able to think logically about tough situations in difficult circumstances. Low moods are short and not prolonged.
- Means that they can cope with their issues.
- Good mental health is when a person is able to function and be successful in their everyday life. If circumstances arise in which the person's ability to function and feel engaged with other people and day to day life I would consider that there could then be a mental health issue.
- Good mental health is being able to cope with whatever happens in life. A mental health issue can stop this from happening.
- Manageable capacity to cope with perdurable emotional or mental stress. Severe or endogenous depression. Borderline psychological conditions, addictions or psychoses.
- Good mental health = being able to live independently and happily. Issues are for example: too anxious to go shopping or to meet friends, depression.
- Structured, understanding adaptable environments that can work with and for the child not against. Minimise anxiety and depression, make life accessible and comforting not scary and foreboding.
- Good mental health means someone is content and confident to go about their daily life. A mental health issue is something in the mind that makes it hard or impossible to lead a contented life, e.g. excessive anxiety, obsessive behaviour, depression etc.
- It is essential to wellbeing or just being alive. Feeling anxious and its knock on physical affects is a problem in addition to the more classic definition.
- Feeling able to cope and manage difficult feelings and everyday life. A mental health issue is when someone experiences difficulty in feeling good and positive about him/herself e.g. being anxious, fearful, depressed.
- Being able to achieve a reasonable quality of life that is not dominated by mood swings, depression and meltdowns on a daily basis
- Being able to live without anxiety (at least uncontrollable anxiety) and fear. Being able to manage your emotions, recognise and deal with them. Mental health issue - anxiety, depression.
- That my child is able to cope with the day without being overly anxious or upset. Anxiety is manageable and doesn't express itself in self harm or other negative ways.
- Prefer not to answer.
- Good mental health means to me feeling positive, being able to cope with the daily issues. Mental health issues can be not coping with everyday situations, eating difficulties, OCD, depression, acute anxiety.
- When your child is slow low and anxious they are harming people and not coping with life!
- Being able to cope and function normally in society. A feeling of not being able to cope and depressed.
- To me it means supporting the people who need support.
- Good mental health means you are able to function normally on a day to day basis. Mental health issues are difficulties with the way you think and feel which adversely impact your ability to function on a daily basis compared with the majority of your peer group.

- Good mental health to me means being able to ‘live’ within a ‘normal’ family/society environment. Being able to maintain relationships and balance any stressors in your life appropriately. A mental health issue is anything which prevents the above being possible. Obviously there are differing degrees of issues!
- Anything that causes immense stress and emotional and psychological problems that prevents a person from functioning as a human being on a daily basis. Which then impact a person’s health and wellbeing and physical health.
- Any neurological disorder which is causing the person to struggle with daily life activities.
- My son I showing signs of aggression and defiance, this to me is a mental health issue.
- It’s not an issue if you have the right help.
- It’s not an issue if you can get the guidance you need.
- Good mental health is a feeling of well-being and being able to be involved in everyday life and activity without overwhelming levels of stress and anxiety and fear. I think good mental health is where life can be enjoyable and it is possible to access and achieve in education or work and be part of the community if you want to. Also about not being isolated, and feeling supported. I think a mental health issue can be about struggling to engage in the world and community and everyday activity because the anxiety and fear around that prevents you feeling it is safe to do. It can mean being isolated and feeling the only way to be safe is to be isolated and withdrawn from the outside world or have very limited access to it. It can be about a loss of interest in daily living tasks such as self-care and becoming stuck trying to achieve daily tasks to the point where it becomes too exhausting to complete them.
- Good mental health is when someone can see the good in life and spend day to day integrated into society, have motivation, able to confront problems practically and feel generally happy. A mental health issue is when a person struggles with these things and can’t find the reason to do them. Mental health issues can be anything from depression to dementia.
- Good mental health is a child without anxiety, depression, self harm or suicidal tendencies; I would consider all of the above to be mental health issues.
- Depression eating disorders self harm anger issues.
- Good mental health = able to live a healthy life independently. Unable to function in even some everyday circumstances.

Question 10: What does “mental health services” mean to you?

ASD participant responses:

- Having all the problems (and therefore symptoms) minimised and having reliable, appropriate and enough specialist support to keep threats at bay (such as threats from assessors/persecutors at DWP, council, etc.) and having access to work, financial help etc. supported appropriately and reliably.
- Feeling good about myself. Having some friends and feeling happy. Not hurting myself or others.
- Being able to function on a daily basis and being able to access work and social activities.
- To be able to live within the community peacefully and have no anxiety.
- Psychological imbalance causing distress anxiety and physical ill health which impact on quality of life.
- Ongoing stable psychological equilibrium.
- Good mental health for me would mean being able to cope within the work place, enjoy daily life and feel happier. For me mental health issues I have are: depression, OCD and anxiety.
- Security.
- I don’t know.
- Extreme Anxiety affecting daily life.
- Help and support.
- Having days when life is not a trial or seems to bring constant worries all the time.
- To be happy and function like everyone else.
- Able to function on daily basis with minimal help. Understanding the situation and people better. Being aware of taking care of self. Being independent. The absence of all the things described earlier which means being dependent on someone to help you in your daily life I would consider a mental health issue.
- Being happy and able to interact effectively and appropriately in most social situations.
- Good mental health means being normal.
- Being unhappy.
- Delay in getting the right treatment
- Being able to cope with feelings and thoughts in a balanced way that is not detrimental to basic living.

Parent/Carer responses:

- Services for people with mental health problems. These often do not cover autism.
- Availability of services to cope with the problems at 9. Access to Psychiatrists with a specialism in Autism & availability of CBT.
- Services that help to achieve the above statement.
- People who might be able to assist with describing, learning, helping, teaching.
- Provision of help and/or support for those (and their carers) with difficulties coping with everyday situations.
- A service to meet the needs of anyone who is experiencing mental health issues, no matter what diagnosis they may have on the autism spectrum.
- A holistic service to help people be happy with themselves.
- A service that will give advice & help when it is needed, and one that also listens to parents.
- The part of the local government that will help if your mental health issues might be a danger to yourself or someone else.
- A team that should support.

- Currently feels like a negative term in the sense that they are the only source of support but are limited in what they can offer. Have had very good support as a carer but do not feel that my daughter has had such good support although she also has difficulty accepting offers of support.
- Support to enable you to lead a distress free life.
- It should mean support and expert advice for those affected by mental health problems; be they the patient, parents/guardians or other family members.
- Professional help for above difficulties.
- It means that services are easily accessible to keep people's mental wellbeing on track.
- That everyone child/adult needs the right to be assessed by NHS not private like we were forced to go to for two of our children people need help/diagnosis not told no help available funding should be there for everyone.
- Someone to go to and offer help/support to you/ your child with issues such as depression.
- Support services to help diagnose and deal with mental health.
- Counselling, CBT, anger management. Talking therapies to assist in identifying issues and implementing strategies to manage the negative response.
- It should mean support, but it feels like failure.
- Separate from, but only accessible through the GP.
- Access to services to support me in helping my don.
- Official help with any mental health issues.
- Help when needed.
- Access to help for services relating to the mind.
- Help with anything going on with you mentally, anything that is affecting your emotions and wellbeing.
- In an ideal world mental health services would provide support to anyone who needed help and/or advice to carers of disabled people.
- In a wider sense: a team of different professionals providing support for people who have difficulties achieving the above. In a more narrow definition a service which provides assessment and treatment for mental health problems which reach the level of diagnostic criteria.
- Having access means we can try and help our little boy.
- Available services to help with those that aren't in full mental health.
- A service that is available when it is needed.
- Counselling & support.
- Professional service to facilitate and assist with mental well-being.
- Counselling, guidance, support, diagnosis, information.
- They are supposed to help but are very inadequate due to funding and staffing issues.
- They should offer therapy and medicate to help elevate the symptoms of poor mental health.
- Mental health services are there to offer therapy and medicate to help elevate the symptoms of mental health issues.
- Supporting different needs and being flexible to adjust to individual requirements.
- Accessing help and support for a mental health condition.
- CAMHS service.
- A mechanism that offers various support methods when it is needed by somebody.
- An available service to support, assist, signpost as necessary to enable individuals to maintain health and wellbeing.
- Someone who can support parents and carers to support children and adults with mental health issues telling them where to go to get help they need to cope.
- Supporting children and adults who are not coping with aspects of their life which are challenging or extremely challenging.
- Looking after /helping people to cope with emotions / feelings in a positive way without the issues listed above.
- Professionally qualified and trained staff - paediatricians, psychologists who can support and guide both child, school and family.
- A range of experts to diagnose and treat using a holistic range of approaches from counselling and CBT to prescription drugs.
- Somewhere to go for support/help.
- Support in helping to manage the above (9).
- Professional help to help overcome mental health issues.
- A support network around the young person to allow them to talk about their feeling and emotions or express through art/drama therapy to enable them to work through some of the issues that have compromised their mental well-being.
- Supportive advice and timely support for families struggling with a young person with Aspergers/ trauma.
- Being able to have a clear access to a structured support and receiving it promptly.
- Mental health services are the last point of call but often unreachable.
- Support information therapy.
- Therapy or counselling from an expert plus medical support from a GP or psychologist/psychiatrist.
- Support and help to maintain good MH.
- Support with issues that mean you do not behave like a typical, rational adult. For people who do not listen to immediate peers, e.g. parents, but need to have other professional people advise them on their behaviour.
- Help for my son to help him manage and cope.
- CAMHS.
- A service that helps to manage/ council your well-being. To help to stop people self harm, commit suicide, understand their condition and manage it.
- Access to support to properly trained professionals.

- Long waiting list, not being able to speak to someone if you believe that your child may have a mental health illness.
- Support for individuals to be able to function ‘normally’.
- Services that provide support and assessment for people, their families and professionals working with people who have social, emotional or cognitive difficulties that impact on their ability to successfully function in all aspects of society.
- Rapid access for acute mental health, established links/relationships for ongoing issues. More specialist areas, better networking with school and school heath, stream line referral and assessment process, the service should not be a post code lottery for service users.
- Support network of professionals, family and resources.
- Where I work – CAMHS.
- Someone to help give guidance, advice, groups etc.
- Services providing support for mental health difficulties.
- Services that support a person to manage and improve (hopefully) any mental health difficulties which may be having a negative impact on an individual’s life and well-being.
- Help for mental health issues.
- Services that can help now to support transition from paediatrician when our son reaches 19.
- Support, information, advice and guidance available 24/7 that can be triggered without specialist referral.
- Support and treatment, access to psychological interventions and talking therapies, signposting to services who can offer support and coping mechanisms, access to medications and mental health workers.
- Support services, talking therapy, access to psychiatric professionals, access to appropriate medications, help and support to learn coping strategies.
- A service that should be available to the public for advice, support, intervention and referral.
- I have no access to any.
- People and resources who can support and advise individuals and their families who are having mental health difficulties.
- Mental Health services are the support services provided by the NHS to deal with the variety of issues that affect the ability to deal with things.
- With contraction of CAMHS and GPs reduced to prescribing exorbitantly priced drugs from Pharmaceutical companies.
- Services to support good mental health: psychologist, therapist, psychiatrist, support worker.
- Services that encompass all aspects of mental health including neurological basis that cause or contribute to a lesser quality of life
- A service which caters for the needs of someone suffering from mental ill-health.
- A let down because of underfunding. Overstretched staff with compassion fatigue.
- A service that understands needs of people who experience difficulties in managing emotions, mood and sense of self. It needs to be accessible, staffed by skilled, compassionate and helpful professionals and essential in understanding the needs of people with diagnosed and undiagnosed ASC and Aspergers.
- Support, information, advice, guidance available 24/7. This is how it should be the reality is far from this.
- A team of people able to help families cope with mental health problems that are affecting their everyday lives.
- The service proved by the NHS for non-physical issues, that is anything that involves their awareness of self and care of self. This would include issues around autism, anxiety, eating disorders, depression and other similar conditions.
- All round support such as housing, employment, respite, medication, strategies and advice.
- CAMHS - therapy, medication, support.
- Someone who can provide support.
- Help and support.
- Supporting those in need.
- Specialist Support from a mental health professional relevant to your specific problems. Diagnosis and treatment but also management of long term issues.
- A service that is provided to care and help anyone who is suffering a mental health issue, regardless of a possible pre-existing diagnosis!
- The trained professionals and clinicians.
- Someone to rely on, to offer useful advice and have real understanding of the disorders being complained about.
- At the moment we are in the process of writing a referral for my son to CAMHS. I would hope that they will be able to help with his behaviours so I can help him to cope better.
- That you get left alone to deal with it.
- Wait 2 years and we will see you then send you away again for 9 months!!
- Ideally it involves a support service where an organisation assesses the person and offers the appropriate level of input to support them in recovery from the mental health difficulty they are experiencing. I think it also needs to be provided by people/ staff who have an understanding, not only of the mental health issue but also the additional considerations that autism presents to recovery. An understanding of the best way to communicate with an individual with autism and aspects of their autism that might affect their ability to understand certain aspects of their illness and how to manage it.
- Mental health services to me would be a service that provides support on all levels to someone suffering a mental health issue: support with day to day tasks, financial support and help with dealing with money, counselling services, emergency contacts 24hrs a day, support both with job seeking and staying in employment and providing groups and meetings with activities to help people feel less isolated.
- A service that provides help and support for children and their families who have the aforementioned issues, now or in the recent past.
- Helping to manage issues.
- Accessible for those in need.

Question 11: Would you/your person with autism be able to recognise if you/they have a mental health problem?

ASD participant responses:
- I may have concerns but would need more expert opinion to be sure.
- It is not always easy to spot but if you deal with a person on a daily basis any change in their behaviour which can impact on their life in my term is a mental health issue. And yes it can be spotted and rectified or helped at the beginning rather than later.

Parent/Carer responses:
- But she might not be able to express it because she has severe communication difficulties.
- Although fairly self-aware they wouldn't be able to self diagnose.
- Don't really know if he could or could not.
- They wouldn't necessarily want to make it known though!
- Yes, by asking the right questions and reflecting back some of the symptoms in a non-confrontational way, certainly.
- Although I do not feel that she realises the extent of the impact it has on her.
- Lives in a state of anxiety, his is normal.
- Hard to tell as they are so young at the moment!
- They know they have but will not attend appointments.
- Not at this stage. He is only 11.
- Most likely not.
- He feels he is now different to other people.
- Aware there is an issue but not in how it affects them or others.
- Would possibly recognise but due to being let down by local services would not know where to turn.
- Understands that he in anxious, impact of others and when, if depressed.
- In part he would realise that he was finding things tricky but would not specifically link this with mental health.
- This is difficult to answer because they are able to on some levels but on the more serious aspects of their mental health they do not recognise how this impacts upon their life and choices they make.
- A child or adult with autism doesn't think they have a mental condition they just see life differently.
- ? Debatable. Very.
- Depends on definition of mental health problem - an awareness of 'otherness' not 'getting it' affects sense of self-worth.
- Unsure.
- This young person has been crying out for help for some time now. The transition into secondary school and the attached higher levels of anxiety have only added to this and she is now experiencing psychotic episodes.
- But unwilling to seek professional help as couldn't take the knock back emotionally if no service or there's a fight for help.
- She just feels lost within herself.
- My daughter knows she's different and this upsets her.
- They do not always realise they are behaving inappropriately.
- Too scared to find out in case people think she is "Mad Crazy".
- The answer is yes and no. He knows when he's anxious but I doubt he works recognise depression.
- They are constantly in a state of anxiety, has become their normal.
- Very self-aware of emotional state but tends to self diagnose from internet resources.
- They are a child.
- They are constantly in a state of anxiety so it is their normal.
- He often says he doesn't feel right but cannot put it into words.
- Unable to understand her emotions.
- My son has no idea he's even autistic.
- They know the difference of the voices in their head is not their conscious as that sounds different, he says it's one voice but they all sound different.
- Young people I work with now seek help more readily or will talk to a trusted adult in school if approached because we are concerned.
- Only since being S3 MHA at The Priory last week.
- Aware of their Asperger's Syndrome and their differences.
- He would experience difficulties but might not necessarily seek help or realise it is a mental health issue.
- Too young and not very emotionally literate.
- My child frequently puts himself down and is unable to have a balanced perspective of himself.
- He knows his brain is wired differently to his peers.
- Except for body dysmorphia.
- He has no concept of what anyone else experiences outside of himself. He therefore does not see the problems he has with functioning normally.
- It takes a lot of time for him to realise and accept, ASD even when he has acknowledged that he has a mental health problem, he is still reluctant to accept any help.
- He understands he is different to others.
- I think he would and has said he feels depressed but aspects of his mental health I am not sure he would be able to articulate his understanding and generally is adamant he doesn't want to talk about aspects of it which makes gauging his level of understanding difficult.

- Having had mental health problems in the past and also a few close family members, it seems apparent to me that a person with a mental health issue can struggle to see the fact at the time, and often it will be someone else that points it out.

Question 12: Would they be able to seek help independently if they have a mental health problem?

ASD participant responses:

- Mostly yes but not always, as I don't realise severity of my condition always.
- Not always.
- I have sought independent help in the past.
- Where is help available no one has time.
- You can take the private route, but it's very expensive.
- There are many agencies, institutes and not today individuals touting magical cure for mental health problems. These can be ranging from diet to supplements to new found drugs. As with any illness these people are taking advantage of the weakness of the individual for their own financial needs. If NHS cannot provide or make provisions for the care of such persons then the least they can do is get a list of practitioners who are good, registered, monitored and compliant for the patients and their families which they have access to. That will probably be a way of dealing with the resource constraints in this environment.
- I have done, but it was very difficult and I had to write to my GP as I couldn't verbalise it.

Parent/Carer responses:

- Difficult to know unless they were completely independent, which they are not so he depends on parents to prompt or know where to go, how to help.
- He won't do or go anywhere without me.
- He's 12, he wouldn't know where to begin.
- We rarely get moments of clarity for our son.
- Very unlikely as struggles to interact with people over the phone or face to face. Finds new situations difficult.
- To young.
- Hard to tell as they are so young at the moment!
- Too young.
- Would not see why they would have to as caught up in own world.
- Would worry about where to seek help.
- Unsure he would go through recognised routes.
- He's 8.
- Again difficult to answer either yes or no because this would vary on a day to day basis.
- They wouldn't know they had a mental condition as it's their normal way of life.
- Very debatable, and may not have patience to go through the system and bureaucracy
- The young person is able to recognise and verbalise that they feel worthless, have no friends and therefore need to hurt themselves. The voices they are now experiencing tell them no one likes them or cares. Fortunately this young person was able to articulate this to an adult and work is now commencing to support her. I am not sure she would have been able to get this support independently.
- No because no one helps.
- They wouldn't know where to start or who to turn to.
- Yes they can, If they believe it is in their best interest.
- She wouldn't talk to anyone or know where to go or who to speak to if she could.
- Too young.
- Completely unable to seek advice independently, completely reliant on carers to enable this and also needs a carer in appointment to speak through.
- They are a child - 9-10.
- To young.
- Selective mute and also anxiety prevents interactions.
- Selective mute.
- Some pupils would but not all of them.
- Too anxious to contact any service independently.
- He would not have that degree of internal awareness to know he needs help and support.
- My child is only 8, but even so has trouble communicating to me (his parent) the things that cause him anxiety. He is unable to speak to teachers and wouldn't seek help himself.
- He will never seek help himself.
- When my son was initially ill he was suffering psychosis and he would not have been able to seek help independently. Now he has recovered from that but still has ongoing mental health issues that prevent him attending college and he would not know how to seek help.
- Although it's doubtful as the symptoms of Asperger's stops him from being confident enough to do these kind of things.

Question 13: What has been the impact of mental health problems on your/your person's life?

ASD participant responses:

- Social exclusion, isolation, finances going down the drain, life disintegrating due to persecution from DWP, council finance people etc.
- Mental health problems whether in children or adults can impact on family life severely. Without support the struggle to cope makes it ten times more harder than it is.
- Had to try and cover up my autism and my bad anxiety.
- I had social services involvement because of having children that would have been affected if I'd been successful in suicide attempts.

***Parent/Carer responses**:*

- Can't understand why other children are nasty to him at school.
- There is a global impact upon our family which puts everyone's mental health at risk.
- Very low self-esteem.
- Direct self-harm and indirect through neglect of all self care.
- Not sociable outside of comfort zone of close family and even then only when in mood.
- Nightmares, physical symptoms - rashes etc.
- Did express challenging behaviours in past on occasions.
- Ended up in prison.
- Response to situations varies on how he is affected on that day - inconsistent.
- Eating paranoid behaviours around food.
- Loss of appetite / self-inflicted reduction in eating.
- Fearful, reclusive and miserable.
- His life has become narrowed and he experiences social isolation.
- As my child is only 8 we ensure he gets adequate physical exercise, but he wouldn't choose this for himself.
- He had to drop out of college. He has not sought work because he can't cope with that and he has become increasingly isolated.
- It has given him extreme low self-esteem, and high anxiety which has resulted in him having very negative and angry days which is really hard as he feels like he has no support.

Question 14: In the last 3 years where did you first go to get help (for your person)?

ASD participant responses:

- Problems finding, accessing, paying for appropriate specialist service.
- Private Counsellor.
- School and speech and language therapists from hospital.

***Parent/Carer responses**:*

- Asked advice from qualified family/friends.
- Autism charities.
- Autism Hampshire.
- Autism helpline who suggested LD Services team.
- CAHMS.
- CAMHS.
- CAMHS.
- CAMHS.
- Community Learning disability team.
- Early Help Hub.
- Educational Psychologist.
- His paediatrician.
- Homeopathy.
- It's taking us 5 years and we are still know closer to getting any help.
- Local NAS group, Facebook group, other online groups, books.
- Local Organisation - Youth in Romsey.
- Local support group and school.
- National Autistic Society.
- National Autistic Society.
- National Autistic Society.
- Portage (referred by preschool).
- School.
- School.
- School and Primary Behaviour Service.
- School nurse after being directed there, GP no help.
- School referred us otherwise wouldn't know where to go.
- Several services through SENCo.
- Social services.

- Told had to go through GP requested a particular service but was told had to go to CAMHS.
- Was discharged from CAMHS at 18 and then had nowhere to go. GP no help.
- We read countless articles and trawled through the Internet searching for help and advice, the groups and people on Facebook have been invaluable in connecting with other people who have the same issues.

Question 15: In the last 3 years, what services have you/has your person with autism accessed or tried to access?

ASD participant responses:

- italk wouldn’t talk to me after first consultation, nor would private “Counselling Together” group in New Forest on grounds of my case being outside their scope.
- Autism assessment under the NHS via the Micklem Centre at Winchester.
- Incontinence service.
- ENHAM.
- I had about 5 different assessments but found out finding treatment was a different matter.
- Italk.

***Parent/Carer responses**:*

- Tried to access/get referred to a specialist Psychologist through Doctor.
- Fareham Mind.
- Maple Ridge Outreach Programme, Occupational Therapy.
- Social Services LD assessment, as they would come to house.
- Physio, Salt, E. Psyc, and others.
- Eastleigh Youth Counselling Services.
- Specialist Autism help.
- GP, Children With Disabilities team (Social Care).
- Couldn’t attain a referral.
- CAMHS have failed many children.
- Private psychiatrist and therapist.
- Educational Psychology Service.
- Private Psychologist.
- Paediatrician and occupational therapist.
- Not available to him.
- Private psychiatrists.
- Psychologist.
- CAMHS for ASD diagnosis, but his anxieties are not serious enough at present to warrant trying to get another referral.
- OT, SALT, mustard seed charity, Early Bird course (NAS).
- Portage CAMHS sleep clinic.
- Early Intervention Psychosis Team.

Question 17: Please rate how easy it was to get help for your/your person’s mental health problems?

ASD participant responses:

- iCMHT sessions difficult to access, rationed and subject to postcode restrictions. Private sessions hard to find, on waiting lists and too expensive.
- Impossible we keep being rejected.
- Even after attempted suicide did not meet the criteria.
- Even if I wanted help for my child it has been one battle after another. He had physical and sensory issues right from the start. I wanted him referred to occupational therapy early on so as to correct his issues when he was younger, but to my dismay and amazement even the doctors told me that that the occupational therapy will not accept autistic children for therapy as they did not fulfil the criteria. Result today he has more problems and again a hopeless referral. It has been left solely and wholly to the parents to find means and methods to help their child. Apart from the school and an occasional help from my GP no help has been provided to my son at any point. The referrals have been done only to be turned down and be told he does not qualify for the treatment, even after being in special needs school. I am not sure if Hampshire has proper arrangements to help parents of special needs children.
- Was told funds were not available.
- My GP initially referred me to italk. This is not very practical for someone who doesn’t like speaking to strangers on the phone.

***Parent/Carer responses**:*

- The initial referral to CTT for assessment from the Doctor was very quick but getting help based on that advice has proved very difficult, such as access to Autism specialist Psychologist or CBT. Referral to a Gender Clinic has over a year waiting time.
- We are experiencing extreme behaviour issues due to anxiety and trauma from bad school experiences, we can no longer live together as a family because of safeguarding issues around the behaviour, and I am told by CAMHS, that my sons case isn’t urgent, and that it’s unlikely he would benefit from their interventions because he is on the spectrum.
- Have been told they don’t deal with autism.

- 7 individual referrals were sent to CAMHS from different people each time and we were only seen once! After the last referral they finally decided to put him on the list for anxiety help and also diagnosis.
- Don't know where to start.
- Especially when in crisis. Because she will not talk to anyone on the phone the crisis teams said that they could not assess her so all I could do was call an ambulance which was likely to make the situation more stressful.
- Declined by CAMHS after GP referred.
- I wouldn't describe it as difficult, but it did require persistence!
- GP wouldn't refer one of my children says referrals were being returned from CAMHS and paediatricians which I didn't believe ended up going private to get a diagnosis at our cost when as a child should of come under NHS.
- Still struggling.
- Applied to but told nothing currently running.
- Our local CAMHS will not see Autistic young people post diagnosis unless they have a co-diagnosed mental health disorder even if the anxiety, challenging behaviour etc. have meant no access to school and having to request a residential placement. If we had received support things wouldn't have got so bad.
- Always seem to have to prove issues.
- CAMHS is underfunded and under staffed.
- GP advised wait would be extremely long and suggested voluntary sector instead.
- No one seems to listen to what is required always trying to fit you into one of their boxes.
- School v helpful. CAMHS process very slow.
- The waiting list for CAMHS is huge. The diagnosis is inconclusive. There are no sensory or anxiety tests. We are discharged with no help or assistance. The school ague my son's problems are due to my parenting. And they see no problems.
- I was advised by CAMHS that as my son had a diagnosis of Aspergers they would not be able to help me with his high level anxiety and easting issues as these were 'not' a mental health issue they were linked with the Aspergers/ASC.
- CAMHS felt he was not an appropriate referral!
- GPs and school don't believe there's an issue so struggle to get any help or support.
- No cover for paediatrician who recently retired, CAMHS will not support my child as under paediatrician care although paediatrician has no appointments. My child has been severely let down by the system.
- Once our son got to 17 the minimal support we were getting via CAMHS stopped.
- Was told to go for a walk daily.
- Went private because specialist help would not be available fast enough. Plus we were shoehorned into italk which did not provide support tailored for someone with autism.
- If we weren't already under Orchard Centre wouldn't of got help.
- I have been told that Autism is a developmental disorder not a mental health issue.
- Refused.
- 3 years of repeated referral to CAMHS from school, GP, Consultant Paed, Diagnostic ASD unit all unsuccessful. Finally secured 4 sessions at CAMHS but service do not usually accept children with ASD.
- We only see paediatrician once a year and no help from o.t even though he is diagnosed there's nothing no help at all not even the second at school.
- Preferred to CAMHS but refused access.
- We went through the GP but they just don't seem to grasp the difficulties, the original referral was rejected as it didn't really say what the problem was and why work from CAMHS was required. In the end I had to phone CAMHS to find out what had happened about the referral only to be told when I phoned that it had been rejected. Once I explained the problems and difficulties to the duty person at CAMHS they put it back to their panel and they agreed to see us. So difficult and frustrating and to be very honest not good enough.
- I am a teacher and found it incredibly hard to navigate the minefield of mental health provision. I dread to think how parents who have special needs themselves or who do not speak English as their first language cope.
- 4 referrals refused by CAMHS.
- Once over 18 it seems hard to find any help.
- CAMHS not helpful: when phoned, they said they did not cater for Asperger's syndrome.
- I had to find a psychologist myself, also had to inform GP how to access help for my son.
- Told by the psychiatrist that having ASD does not qualify him for support so he added OCD so as to be able to treat him. However, as my son has refused medication he has been discharged now and we are back to square one.
- There wasn't any help from CAMHS Fareham and Gosport.
- There is no help you are left to deal with it.
- We had a delay in getting my son seen by the mental health team as referrals had been sent to the wrong service. Once we were seen then the crisis team visited for 2 weeks and then we were referred to the Early Intervention Psychosis Team and we saw a nurse from their weekly for a year and a half. We have now been signed off that team and there is no ongoing mental health support, unless we request input from the mental health services. The feeling that my son's anxiety is autism related means that we are under the learning disability team for support. However because my son has an IQ higher than 70 and is not classed as having a learning disability he is not eligible for the input of the LD health services.
- It seemed that whoever we spoke to just wanted to focus on one subject, either the autism or the mental health, it was frustrating that the two issues couldn't be seen as connected and dealt with as such.
- Constantly cancelled appointments leaving an appointment not knowing when you will hear from them again.

Question 18: How long did it take to get help for your/your person's mental health problems?

ASD participant responses:

- Specialist service in Dorset (Dr. K. Sutton) but rationed and not available to Hampshire residents.
- They still haven't helped.
- We're not seen due to waiting lists being so long.
- Formal diagnosis was approx. 9 months. Other mental health service access was mostly much quicker.
- Ongoing.
- My Doctor was highly sceptical.
- The referrals have been made it takes sometimes more than 6 months to get a call, only to be told that we will not get the service due to the eligibility criteria not being fulfilled.

Parent/Carer responses:

- That is only the initial assessment time (see 17 above) access to further help is now in the 4-6 month period without access as yet.
- Still waiting for further assessment.
- We are still waiting.
- Had been depressed much longer without support other than GP. Community health only on board after suicidal tendencies arose.
- 3yrs to get a diagnosis.
- Variable depending on situation.
- Never have.
- The EHCP processing was the longest - took well over a year all told.
- Has still not got help after 2-3 years.
- 3 years.
- My child had been assessed before starting school.
- Too much re re re referring.
- I have not got any help.
- We never did get help.
- This was once EYCS contacted - otherwise still waiting.
- Still not got the help we asked for, what we got was waste of time and money, was not autism specific 'professional' refused to engage autism diagnosis and respond accordingly.
- School very swift to act. CAMHS very slow.
- I still feel that there is no help.
- No help provided I was sent leaflets through the post to help me with the care in respect of the above with my son.
- No one seemed to be able to take a referral for him due to his challenging behaviours and variable agreement to engage/not engage.
- GP School or CAMHS wouldn't support as didn't believe there was an issue.
- This was telephone support with paediatrician. Paediatrician has no appts available.
- I think this was the time...
- 2 years being bounced between paediatrician CAMHS & GP for dx. 15yrs old before dx. Disgraceful.
- Ongoing.
- Still dealing with it.
- 5 years and still no closer.
- Emergency appointment waited nearly 6wks.
- Never had help.
- Over 3 years of repeated referrals including emergency referrals by GP for suicidal thoughts - still unsuccessful.
- Still no outside support.
- From the point at which we approached out GP to our son seeing a CAMHS worker 10 months and by then his problems with anxiety and school had escalated and we had to remove him from the school. Something which could so easily have been dealt with and nipped in the bud, we are today back at square one.
- Only because I paid to go private. I was not willing to sit on a waiting list for up to a year.
- Help restricted as CAMHS testing for ASC and therapies able to offer not appropriate for children with ASC who are unable to identify their own emotions.
- Still trying.
- Age 15 2-3 months, age 20 no help.
- Went to private psychiatrist as CAMHS refused to help.
- I had to persist and because it was evident my sons mental health was deteriorating quickly, we did get referred to local CMHT.
- No help offered, but appointment came through within this time frame.
- Still waiting really nothing ever works/lasts.
- Eventually got help through special school post 16 unit referral.
- Still trying to get the right support.
- I went to Harley street London in the end to see a private consultant.
- It was a crisis situation so I think we were referred quickly.
- Again because the two issues were made to be disconnected he received medication for depression within a week but had to wait almost 2yrs to see an autism specialist for help in treating the real issue, people with autism need special help when dealing with depression and anxiety they don't respond to the usual help provided for others.

Question 19: Did the person or people you saw put your/your person’s problems down to their autism?

ASD participant responses:

- They admitted to not understanding autism, and said they might be able to learn from my case.
- Not sure about this.
- They didn’t know how I could have autism because I “could speak” so I had to explain to her.

Parent/Carer responses:

- Told his behaviour might improve with age.
- We just had a Choices appt. Although I felt we were listened to, my son found the experience extremely traumatic and by the end was curled up under my chair in a foetal position in silence. I felt the questioning of him was insensitively done, considering his diagnosis.
- No idea.
- I don’t know, there may be more learning difficulties that have been unidentified.
- Initially problems were put down to personality disorder.
- As we saw someone privately for diagnosis we were fully kept updated and included in meetings and our child was diagnosed quicker than NHS lists.
- Once seen they were brilliant, but it took 3 years, and now diagnosed we’re on our own again.
- To ADHD.
- And other learning problems.
- Yes and looks like not going to get anymore help now an adult.
- Did not seem to engage in any autism specific assistance.
- Answers to Q 20 re CAMHS.
- CAMHS - suggested his problems might be connected to autism - he was not at that time diagnosed.
- In our case early trauma also impacts our son.
- Have NOT actually got any help as yet.
- Very much so “it’s not our field” you should be accessing Hampshire Autistic Society
- Just said it’s sensory issues which they can’t deal with and no help for them.
- They had no Understanding of Autism but were receptive to learning about it. I had to educate staff.
- The EIPT nurse didn’t initially put the problems down to his autism but over time and with the input of a specialist psychiatrist the feeling was that the ongoing difficulties are related to my son’s autism and I would agree that what my son talks about as his fears and difficulties relate very much to fitting into the world, understanding people and wanting to get things right so he doesn’t get in to difficult situations. These have been issues throughout his life but reached a crisis point in his second year at college.
- Accessing the mental health team felt pointless as they just didn’t seem to understand the issues fully.

Question 22: Did you feel that you/they did not receive appropriate treatment because of this?

ASD participant responses:

- Treatment was cut short without warning and did not focus on eliminating social causes of autism mental/physical health problems.
- Don’t yet know if there will be any help.
- Was very anxious.
- I felt that some of things said to me were not explained enough and did not take into account my difficulty with verbal processing.

Parent/Carer responses:

- The choices appt wasn’t a treatment, just a signposting exercise.
- Selective mutism meant a talking therapy was not appropriate.
- Would prefer for them to be assessed for autism now.
- Went on to other help advoiding main issue in end when he was left to go alone then got told sorry can’t do no more it’s part of his autism.
- They were brushed off as autistic, and no help given.
- Daughter was firstly diagnosed with severe depression as soon as she had the autistic diagnosis we were pretty much dismissed by CAMHS as if having a diagnosis magically solved all our problems.
- Already awaiting appointment with paediatrician.
- They couldn’t offer the specialist help he needed and by the time he was dx there wasn’t much service.
- Have NOT actually got any help as yet.
- Discharged after 4 sessions as all issues related to ASD - my child feels this has not been helpful.
- He is diagnosed but said because it’s more sensory issues he has they can’t help.
- Only with certain aspects though.
- But unsure what “appropriate treatment” would mean here.
- We had to wait until the mental HEALTH issue became a crisis rather than getting help early on.
- They said oh that’s just the ASD, we can only see patients with conditions that can be treated. Autism can’t be treated, you have to manage.
- I think we received the appropriate treatment for the acute phase of his illness but there was a huge lack of knowledge and expertise about autism which I think hampered things and did make us feel unsupported at times and possibly seen as difficult or over involved.
- The physiatrist told my son that he did not understand him and that he confused him.

Question 23: In the last 3 years, do you feel your person has accessed mental health services often enough for their needs?

ASD participant responses:

- Many of my problems stem from my social situation (unemployed, on benefits) and the way society treats me, which mental health services appear unable to do anything about.
- We keep being rejected.
- The system is ancient. It depends on GP referral or a healthcare professional's referral. You cannot directly talk about your concerns to any professional having experience in that field directly.
- I seem to have run out of options within mental health services to help me now.

Parent/Carer responses:

- After a particularly traumatic evening daughter was taken to hospital by ambulance with the police as she couldn't trust herself to not do something harmful, after several hours in A&E a junior doctor asked her if "she still felt like killing herself" and when she replied "no I'm too bloody tired" was sent home with no formal assessment or future appointment.
- Need an autism specific life skills plan.
- CAMHS process slow- we need to know how to help him.
- I feel like no one believes me there is an issue and no one will listen to me.
- Probably not but CAMHS didn't really help much anyway.
- Past 17.5yrs there is no service he can access. Just get told he doesn't meet criteria whatever criteria is.
- Have NOT actually got any help as yet.
- Only was seen during "Breakdown period" then it was only a Parent/Carer appointment.
- Has never.
- Has needed ongoing support which has not been available on NHS... ended up having to pay privately and even that was difficult to obtain as services were reluctant to take ASD children.
- He should be getting help from OT SENCO and seeing paediatrician more.
- Has received none.
- My son was discharged in the summer and now the problems are back and we are back at square one.
- None given yet.
- I think that he would have benefited more from increased frequency of interventions.
- Sometimes post diagnosis parents are unsure of who to seek help from once discharged from CAMHS.
- She didn't understand or resisted being "different".
- All support stopped at 18. Now beginning to access again as crisis point against reached.
- But only because I have a lot of knowledge and have advocated for my son.
- No services accessed as yet, other than diagnosis, but I worry as he is highly anxious, that we may need to seek help in future.
- There has been no help for my son.
- I say that with reservation. I think he very much needed the teams for the psychosis and that was helpful. I feel that now the crisis is over it reverts back to the care being our responsibility and I also feel that I have real reservations of how much mental health input I would seek in the general mental health services because of their lack of knowledge of autism and my son's vulnerability. I feel it is quite likely he would not be supported in the right way if there is little knowledge of autism and that could lead to a worsening of his problems. My instinct is to try to manage without the services because I don't have a lot of confidence that the help would be trained enough in the very important area of his autism. I also worry greatly about his not being listened to, directed because he is a placid and easily anxious person and unable to assert his right to choose and that would leave him more vulnerable to a deterioration of his mental health. All of that anxiety on my part is based partly on media coverage or campaigns for people stuck in inappropriate mental health facilities, and in a small part to some of the attitudes of mental health professionals we have dealt with. The nurse who saw my son was very good but I think Doctors who openly acknowledged their lack of expertise in autism would also become defensive and critical of our concerns. Comments from one professional in one of the teams were actively unhelpful and would put me off contacting them again for "support".
- Only because we seeked a second opinion, and had to fight very hard to get him the help.
- I feel like I provide all of his support, sometimes to the detriment of my own health.

Question 24: How has caring for your person with autism affected you and your family? Has it led to health problems, mental or physical?

Parent/Carer responses:

- Affected marital relationship, parental friendships as children do not like non family in the home or parents to go out and leave them.
- Always need a plan B if it is a difficult day for the YP.
- Am frequently depressed and suffer psychosomatic pain.
- As a family we are restricted with what we can do during the weekends.
- Both for my husband, myself and my younger son in the past.
- Breakdown of family/his parents. Physically exhausted. Always tired/run down. Constant colds etc. Low immune.
- Caring for my son since his mental health illness became acute and following that has been very difficult. Initially it was deeply distressing and we felt powerless to help him which was a new feeling. With his autism I think I felt we always understood and were able to support him as well as we could. His psychosis was very frightening for him and all of us. as a family we didn't get

much sleep, it was hard to rest at all as he was screaming or shouting or pacing or hitting himself. He needed 24 hour support. He couldn't be left at home alone at all. I had to abandon plans to find work and have only just started looking nearly two years on from that. We have not felt able to travel to different places, have had to tailor most family events to the needs of our son and not been involved in many things because of his needs and difficulties. We have often not been able to do things as a whole family and this has caused resentment between siblings. Our lives have been dominated by the very specific needs of our son and for the most part we have managed that very well. Since his mental health illness it has created different issues and difficulties. His sister struggles to deal with his increased rigidity in what he can cope with, his altered sleep patterns that keep her awake and have affected her sleep, work and energy at times. I have found the last 2 years incredibly difficult in terms of being unable to achieve my own goals of working, having spent the last 16 years at home supporting the children and also in terms of being restricted to the house for a lot of the time as I wasn't sure my son would manage being left without becoming over anxious. We are not very cohesive as a family unit. My husband and I have separated in the last year and the vast majority of care, physical, emotional and educational etc. has been mine. So caring for my son has had a massive impact on all aspects of life for all of us really and continues to do so with me especially but also my husband and children. Health wise I think it has not impacted especially although I became Vitamin D deficient because I was out so little. My daughter missed sleep and that impacted on her ability to cope with work and her feeling very low. I have felt very low at times, and felt I was struggling to cope and it has been a very different experience to support my son through his mental health problems than dealing with his autism alone. It has been difficult, stressful and sometimes isolating over the years. Our lives have not had the freedom that most of our friends have and as their children have become less dependent and gone off to do their own thing, our son has become increasingly dependent and restricted in what he feels able to do. It is difficult not to spend most of the time worrying about when he will recover and to what degree, and how that will affect him and all of us. His sister feels a responsibility for her brothers (our other son has a disability following a road traffic accident) and she sees that as being a part of the rest of her life.

- Caused a lot of heart ache.
- Depression - overload of work, affecting family, siblings.
- Depression in myself, Stress, has an impact on siblings. Constant fight to get any help or benefits young person is entitled to.
- Depression, weight gain.
- Everyday life is hard and a struggle dealing with constant upsets meltdowns and break downs.
- Exhausted.
- Family stress and difficulties.
- Have NOT actually got any help as yet.
- Health and well-being surely. Very stressful and emotionally & physically violent. For daughter totally voided her secondary school experience and achievement.
- Highly stressful often unable to get out with him unable to have any adult time as cannot leave him with anyone else.
- Huge impact on family life to the point of near breakdown.
- Huge impact on rest of family. Serious stress for parents and sibling and serious physical health problem for one parent.
- I am a widow and have developed Fibromyalgia, which is strongly linked to stress. I am also chronically depressed and find trying to get the appropriate level, and kind, of support for my son soul-destroying.
- I am always tired and make mistakes in own work.
- I am exhausted. I reduced my working hours and have now handed my notice in as a teacher. My older son can't do things he would like to. He has a lot of responsibility looking after his brother. Sometimes he is jealous and resentful. We all have to live in an atmosphere where there are outbursts. Very stressful.
- I have given up work in order to be able to care for my son. He attends mainstream school but only just manages, and wouldn't cope with any additional after school care. I feel well supported via parent support groups, and I read and inform myself of the best strategies to help my son. My son is occasionally violent (when he is frustrated during a meltdown for example) and often says he wants to die. He is a very rigid thinker, and gets upset by small things. We do our best as a family to support him and to help him think positively and to see his own strengths, and to work out coping strategies for situations he finds difficult.
- I have had depression and stress myself and have had periods of leave from work to take care of her.
- I have left work due to my daughters needs.
- I suffer with anxiety and sleep problems.
- I'm medicated to cope with the children's behaviours. Struggle with working consistent hours. We just lurch from one incident to the next.
- Impact on partner's mental health as he also has a chronic ongoing physical disability so find it harder to manage stresses.
- It can still be very challenging, as we get no help, he only goes to school for a few hours as he can't cope, he has extreme anxiety every day. He can't go out or socialise as he finds this difficult and needs a very strict routine.
- It does make you want everyone to clearly state what they mean.
- It has affected all the family including our 10 year old, my husband and I both put our own health issues aside to help him, we also gave up our business to help and support him as our time trying to get help for him was a constant fight!
- It has affected the mental health of her brother, who grew up with her.
- It has been an incredibly hard and very lonely place for me as his mother. Is has had an effect on our marriage, and with regards to our other children it has meant that they have had limited experiences. We have not been able to just jump in a car and be spontaneous at any point. Everything has to be planned, researched, measured and agreed in advance, and then may still be very difficult. We have not been able to go to museums, different places to stay on holiday, different restaurants, parties, family get-togethers. The list is endless. Things are slightly improving now, he is 13 and in a very supportive school environment. Despite this environment, he still finds eating with anyone other than his immediate family very hard and is therefore very underweight, and he still struggles hugely socially, even with cousins and grandparents. His anxieties are very high. It was school who asked me to

obtain the GP referral for CAMHS. I have repeatedly had to use every coping strategy possible to help manage family life and this has at times been totally waring both mentally and physically.

- It has been mentally draining.
- It has been mentally draining, physically demanding.
- It has changed the family dynamics affected my health irreversible damage to my marriage.
- It has led to health problems for myself and my other child.
- It has led to hugely increased stress levels. It caused my older daughter to move out, it led to me being off work for 6 weeks last year. It has an impact on all areas of life and complicates any arrangements for family get-togethers which are very important to me.
- It has meant I cannot work, we have little time together as a couple because we have no family or babysitter who can look after my son in the event of an issue, my mental health has been affected, my daughter has to see an ELSA at school and her young carers group to help her peace of mind and get her some time just for her.
- It has not changed anything.
- It has put a huge strain on our family, physically and mentally.
- It has put strain on the whole family and is mentally and sometimes physically exhausting.
- It has taken over our lives and had a massive impact on his sister.
- It is exhausting both mentally and physically. It negatively impacts on all of our family on a daily basis. Every tiny thing has to be battled for and it never ends.
- It is extremely difficult. It affects everyone mentally and physically, especially siblings.
- It is very disruptive for the entire family. Our son controls our lives not intentionally but his needs affect us all. Physically we are exhausted and mentally drained.
- It makes life challenging sometimes but we have devised coping strategies ourselves to make our family stronger and cope better.
- It was been stressful. But he’s making a lot of progress and is much happier.
- It’s a daily struggle no sleep and no school there is no break it’s very hard.
- It’s a role I haven’t chosen. My 20 yr old should not have to be reliant on his mum all the time. This has a negative impact on me because I have MS and I am also a carer for my father who has cancer. We get no support so my younger daughter does not get enough attention.
- It’s affected the whole family depression and Stress, loss of work as my daughter only attends school 2 hours a day. My youngest has also suffered as she has had no support so she’s struggling to cope emotionally.
- Its affecting my work, my mental health, and that of my wife, we are constantly trying to support our son but feel so unsupported. Got to the point where I’m feeling low and need to see the GP for myself.
- It’s been a huge strain but our children are unique as a parent you fight for them but the stress has been unnecessary if CAMHS did their job properly GP didn’t turn people away and diagnosis was easier instead if over six month waiting lists. The only health problem has been stress.
- It’s very challenging for both parents and does cause arguments. I am continually stressed and on anti-depressants.
- Mental health challenges: hugely stressful fighting the education system, bouts of depression, marital problems, lots of arguments.
- Mum and dad’s relationship has been strained, but both were strong enough to seek help. Talking therapy is a godsend! Things are improving over time. Younger siblings seem unperturbed and accepting of the condition.
- My husband and I are stressed, worried and tired all the time. I cannot go out for a day in case the school calls me to come in.
- My husband is signed off work with stress and has started a course of antidepressants. I am having counselling for stress and anxiety. The impact on the siblings (also on the spectrum) is something I have to try and manage as best I can. But it is affecting their school work, self-esteem, and ability to have friends around and what activities we can do together. Now that my son is having to stay with a relative we are all traumatised by the separation, alongside the behaviour which led up to it.
- My marriage broke down and ended in divorce, I have been on anti-depressants for 4 years, I have had therapy counselling and couples counselling.
- My whole life changed everything has to be locked and he has to be watched 24/7.
- No.
- No, it just means that we have to be more careful in particular situations and avoid some places: Noisy places with too many excited other children.
- Not at this stage - he is much loved.
- Oh boy yes. We have been at breaking point at so many times. We live ‘hanging by the thread’.
- Our lives are extremely hard and challenging.
- Physical violence against us, emotional effects on siblings, lack of sleep, having to give up career. In desperation requested residential placement.
- Positive experience as regards to understanding my child’s behaviour and her challenges and strengths as well as learning about those in the rest of the family. Currently under a period of high stress and meltdowns due to a recent bereavement, this has caused a great deal of disturbance to the rest of the family and a feeling we no longer have the skills to support her and little support available for paediatrician.
- Put a huge strain on our marriage and the mental health and well-being of our two other children.
- Rest of family has to cope and always to compensate. Family separated.
- Significant emotional strain on parents and sibling. Some physical signs of stress and anxiety.
- Social isolation- depression- unable to go out- losing touch with family.
- Stress depression limited social life isolating.
- Stress for the family; mother unable to work and stopped career as a nurse ; siblings feel he gets all the attention and family days out and holidays have to be around his needs.

- Stressful, putting strain on my marriage, exhausting.
- The strain put on our household has caused, depression in adults, decline in physical health, which in turns raises the anxiety of young person even further. Vicious circle!!
- Very challenging. Exhaustion from lack of sleep as they don't sleep, living with someone who tries to control the environment to reduce their anxiety as they are unable to manage their emotions. This has increased my own anxiety as I have to try and manage daily life to reduce her anxieties, which is difficult and requires so much thinking ahead to pre-empt difficulties.
- Very difficult to remain unaffected by his needs & very time consuming accessing the system.
- Very hard living with my son me and my daughter suffer depression.
- We all ended up on antidepressants, missed work through stress and I ended up giving up work.
- We are stressed both physically and financially. It is exhausting trying to get help from people that will not listen to what you are saying and are inconsistent in the information they provide.
- We are exhausted physically and emotionally.
- We are our son's parents and one of us has developed anxiety & depression related to caring for our son. My physical health has become worse. I'm now permanently at home and my husband can only manage to work part time.
- We have all suffered mentally and physically. We've been sworn at and injured.
- We have changed most things about how we approach life as a family. We go out less. Me and my husband used to argue a lot about how to manage my son, this is better since we have a diagnosis.
- Yes.
- Yes all affected mentally very concerned I as main carer am exhausted.
- Yes all of the above.
- Yes but I have more than the one son with ASD.
- Yes it has led to both physical and mental health problems for myself, it's hard to support someone when you don't fully understand life like they do, in particular the bad days when his mental health is low we really do struggle. Our children have learnt to adapt, they understand that we can't do a lot of the things normal families do without a lot of pre-planning and preparation. It's been particularly hard for us as it has become apparent that our 12yr old is autistic and suffering the same problems.
- Yes lots of stress.
- Yes mum chronic anxiety.
- Yes, it has been more stressful with little support. It has been a strain on family relationships, and I have suffered from depression partly due to this.
- Yes. I've had to stop working. Breakdown of parent's relationship and stress on younger sibling.

Question 25: What are your main concerns going into the future for your person with autism?

Parent/Carer responses:

- Lack of support, constant lack of funds, changes.
- Lack of individualised services; lack of awareness in the CCG of importance of Personal Health Budgets to provide individualised care & detailed care plans.
- That his state of mind will deteriorate without access to the people who could help.
- How he will be able to cope with secondary school. Will we receive any help or training to be able to deal with his emotions, behaviour?
- Hoping that there will be enough support for them to get through school/further education and into work and hopefully live independently.
- Unless my son receives specialised help soon then a major incident could occur. Then the harm will have been done.
- That they will not get appropriate support.
- Only living relative is abroad so who cares when I'm gone?
- People won't listen properly to her as she can't verbalise her needs. It is easier for professionals to just guess what they want you hear rather than help.
- What will he get from the education system, as he is really struggling in mainstream school? Will he get his EHCP so he can go to a specialist school? What kind of job will he be able to have? How independent will he be, especially when we die?
- How will she cope at school moving forward then work later.
- How she will be able to get help to come to terms with her difficulties and learn to have hope for the future. Due to her high level of self harm she is not being offered any psychotherapy but it feels like she will be stuck in this cycle for ever unless someone takes a risk and takes her on.
- How independent they will / will not be. How they will be treated by the - generally ignorant - public.
- His future employment, his living accommodation, his mental and physical health, his inability to get his needs communicated to anyone who is not close family.
- Whether she will be able to function in everyday life.
- That as adults more care needed not just parents to deal with it more support groups funding and stuff to access for them is needed.
- How they will be as they become older. Depression and anxiety does concern me a lot.
- That the system isn't set up to support HFA kids in the mainstream education environment unless their education is suffering but teen years are confusing socially and emotionally for these kids as they are logical and struggle with things NT children pick up instinctively which makes them appear different. Lack of support will severely impact on their ability to remain in the mainstream and fulfil their potential.
- Exhaustion and strain on family life and marriage.
- If they will make friends. Spend time without being with me all the time.

- How they will learn to look after themselves, or get support they need.
- How will they manage secondary school how will they function in his life.
- Life on his own, how he will be treated as a teenager.
- Being understood and getting the help he needs as he is high functioning and his underlining needs get missed because of it.
- He's going to get bigger and stronger, and I won't be able to keep him safe or others near him.
- He is currently not getting any schooling and without help he will become a delinquent with no education and no job.
- Where will he go, what man will he become, who will protect him when we cannot.
- Unless he receives help to recognise and deal with his emotions without resorting to serious violence he will end up in prison.
- Because of HFA his difficulties are less visible and are minimised. He has already experienced bullying and is prone to low self-esteem. I am worried about him blaming himself for his difficulties. This can lead to all sorts of mental health problems.
- Being able to live a happy life.
- She is naive in the extreme and would not cope living on her own or trying to live a fully independent life.
- What doors will be shut because she has a formal diagnosis and future relationships.
- How they will cope when stressed if I am not there.
- That he has life skills to be able to access employment, shops entertainment etc. when we are not around.
- He is very bright but isn't achieving. I worry about him feeling frustrated and isolated. He struggles socially.
- His and our health suffers greatly. We do not lead full lives.
- He's 14 so will soon be reliant on adult mental health and from personal experience they are utterly unprofessional and useless, don't listen and lie.
- Social exclusion- keeping him safe- being unhappy.
- Their independency.
- In the near future his low self-esteem and confidence. His lack of ability to record in any of his lessons at school due to the fact that he really feels he is not capable and unable to be remotely good at completing any work. His social interaction with others - peers and extended family is very limited and is hugely 'mood dependent'. His ability to transition away from his senior school to sixth form education. He potentially will not have the ability to work as a result of his anxieties. He is still very nervous of new environments, and the potential of fire alarms sounding and burglar alarms sounding.
- Lack of resources, support, awareness and the apparent easiness for child to 'slip through the net' without a constant fight from those in family.
- No one will listen to me or support me with my child's needs and assessing her according to give her the help and support she will need to support in school and out of school.
- Mental health issues and depression.
- Appropriate secondary schooling. He has had has one or two excellent teachers who have met his needs - others have not and this causes extreme anxiety. He will not cope with the continual changes in a secondary situation with a variety of staff.
- That you have to fight everything to get the right help. Too little understanding amongst employers. All supports groups are during working hours. There is very little local help for working parents with an autistic child.
- How they will manage as they become an adult.
- Living independently as a young adult.
- His poor decision making and troubles will land him in such a mess he cannot get out of it.
- That he will be left alone when I am gone.
- Her decline.
- That she will get worse because she is not receiving the help.
- That he won't be able to live independently.
- Learning to cope with her depression and living independently.
- Have NOT actually got any help as yet.
- Managing violence.
- Getting the right support.
- Transactions from secondary school to college, to future employment. Living independently/general life chores when they are left without parents.
- That they will be able to function in everyday life.
- The service continues not to recognise that just because some has ASD or traits associated with other conditions, that the person cannot have a separate mental health issue independent from their overall condition, this is simply untrue, unfair, and discriminating. This has to stop.
- My son has no independence at all aged 15yrs and so the future looks very bleak.
- Who is going to help him? Especially if I die. How is he going to know where to go to get help with housing/living situations and help with depression/anxiety etc. Will he end up homeless or suicidal?
- He will not receive the support he needs to lead a 'normal' life.
- What support will be there for him?
- As he is getting bigger and stronger worried about his violent out bursts.
- Independent living.
- That he is not going to cope in mainstream school despite extensive support. That he will not be able to cope with the new GCSEs. That he will not be able to live independently as an adult Therefore what happens to him when we are gone?
- That she won't be happy or find her place in life. That she will become more and more depressed and suicidal.
- That life will always be a struggle to access services for help. Not enough funding Not enough understanding and support and horrendous waiting lists.

- People do not accept him he’s been called a paedophile because he was jumping a lot on his trampoline, how will he cope to live on his own as he hardly eats won’t go to shops won’t go on transport. Won’t go anywhere where there are people.
- They are not working and can’t find the help to support with this. Worry they will never get a job and be independent which is what they really want to be.
- Disappointment at being bright but not able to find employment. Discouragement, low self-esteem and likely depression or suicide
- Being able to live independently and have a job.
- His development particular that of sexual awareness as he goes through his teenage years, settling him in to senior provision and what he can access after that.
- How he will access meaningful employment and manage life as an adult.
- Reduction in funding of services. I am furious that the only provision is from CHARITIES. My son has a right to good services, not just based on the goodwill of lovely, underpaid people in the charity sector. There shouldn’t be so many agencies - TOO MUCH INFORMATION campaign should be applied to the myriad of different charity and voluntary services we have to try to access.
- Will mental health services recognise his specific needs? Will they have a thorough understanding of mental health needs for someone on autism spectrum? Where will he live and who will support him? What will happen this when I’m too old and unable to advocate and fight his corner? Many major concerns.
- That nearly the whole of life involves social interactions, and he struggles with this, so it may be difficult for him to manage in life. Currently he is in primary school, so our main worry is day to day issues, and then whether he will cope with secondary school. But longer term I also worry if he will be able to hold down a job, and support himself, and how he will manage when we are not around anymore.
- No treatment or support is being offered for an eating disorder.
- Suicide symptoms getting worse.
- The unknown. How will they cope as an adult when there is no help out there for them.
- What will happen to him when I can no longer care for him? How will he support himself and become independent when he keeps getting turned down by social services for support. What will he do if he loses DLA and other benefits? Will he ever have a job?
- That all support will stop because he has difficulty engaging with it, and cannot seem to understand that he needs to help himself.
- The lack of services in mental health.
- How will he survive without me? Where is the constant support going to come from?
- Finding the right school as she has been in a pru for a year now.
- His aggression.
- That he goes to the right school and learns to control his aggression.
- My son’s recovery, fear of him becoming ill again. His care and whether he will be listened to, know his rights and have them respected. My son’s being able to engage with the world again if only to the degree he did before his illness and how people will treat him. He wants to get back to real life but needs massive support to get there. I worry about when I am not here anymore to advocate for him. I feel he is very vulnerable to feeling he has no say in anything, that he is fearful of people so will do what he is told regardless of whether that is what he wants. I worry about him being exploited or bullied and I know he worries a great deal and this impacts on his ability to do a lot of things. I am concerned that if he is dealing with professionals who do not understand autism they may misinterpret what he says or means or make snap judgements because they don’t take time to explore what he means to understand what the difficulty is.
- What’s going to happen to him when we die! That’s why we fight so hard for his care as we know that the services are not there.
- I have concerns that if I was to stop supporting him and feel like I couldn’t be with him anymore then he would have zero help and support as he doesn’t have any family that help him. I fear he would continue to be unsupported and become left out of society. Going into the future together I feel that not much will change to what we have now, I worry we will never receive the help and support we need to live a normal life.
- That no one has helped my daughter learn coping mechanisms for her anxiety so when she encounters more new things we will have the same problems.
- Acceptance his severe behaviours.
- Him being unable to live a normal (functional) life.

Question 27: Please outline your experience of the transition, specifically access to mental health services during transition and care received post transition.

ASD participant responses:

- No responses.

Parent/Carer responses:

- Absolutely disastrous. The CCG has no understanding of autism, and has a stigmatising attitude towards people with autism and their families.
- There was no transition to Adult Services as far as I’m aware we just stopped seeing the CAMHS Psychologist when he reached age 18
- Transition was fine. Since then it’s been a quick chat.
- Nothing accessed more needs to be done for support.
- She is in college and 17.
- No transition, no help whatsoever.
- Supposed to be but still waiting for EHC to be completed - over 12 months now.
- There has been no transition.

- He’s transitioned but he didn’t receive any services.
- None.
- Discussing.
- There is no transition!!!!!! You Have to run around doing it yourself, why should we have to run around doing all the work!!!!!!!!!!!!!!! You, the NHS/Council are not helping, because you cut the damn funding and make it so damn difficult to find someone to actually take notice and help.
- About too but no adult help available.
- There was no transition!
- There was no transition as condition deemed ‘untreatable.’
- We had a transition meeting at which the adult service said he was not bad enough as CAMHS had stabilised things. Had to wait for crisis before beginning a new referral and start at the bottom of the waiting list again. Medication continued as prescribed by CAMHS but no one was monitoring its affects -just got repeat prescriptions.
- Not good as she has high functioning Asperger’s they think she has intelligence to cope.
- There was no transition. I got a call from CAMHS on his16th birthday to say his case was being closed that day. School helped us with a referral to adult mental health but we had to start again from scratch. Appalling and had terrible impact on my son.
- My son was only diagnosed as autistic when he was 18yrs old and waiting to be transitioned to adult services. I had been trying to have him assessed from 18mths old. He had been in ‘the system’ since he was 10yrs old, being seen by several different professionals, and even had a short stay in Leigh House, but was discharge from this Adolescent Psychiatric Hospital for being verbally violent and aggressive!! He was 13yrs old and deeply traumatised and depressed. Between then and transition to adult services he has received various therapies, which he has not been able to engage with fully because none of them have been autism friendly. Since receiving his diagnosis and the transition we have been told about the lack of training, experience and understanding of autism from every professional we have met. There have been efforts at trying to engage my son with Psychotherapy, but again, not autism specific. We continue to keep trying!!!
- No help no care no provision.
- Rowan’s transition assessment was rushed because he was already becoming unwell and he wasn’t in a place to be able to contribute to the assessment in any significant way. Two days after his 18th birthday he suffered psychosis and I have detailed the input of mental health services after that. We now have no input from mental health services but have a social worker from the LD team and have had the input of an ‘autism ambassador’ on one occasion. We are now in the process of reviewing his assessment as he is now in more of a position to contribute to it and I am helping him with that as he is reluctant to meet professionals and the do not visit frequently so it would take forever for the assessment to be completed otherwise.
- We feel that there was no transition for our son, he was left!

Question 28: How far do you agree with the following statements? Since accessing mental health services in the last 3 years......

ASD participant responses:

- Due to society’s attitude towards me (e.g. the threatening persecution from DWP) my mental health, physical health, financial and general well-being are all declining. I wonder whether life is worth living.
- No longer in mainstream primary school.
- None.
- I am not trying to kill myself anymore!

Parent/Carer responses:

- There has been a marked deterioration because we are still waiting for help.
- We as parents expect less from him, so he is less stressed at home.
- On the whole life hasn’t really changed we are still fighting as much today as before diagnosis to get everyone to recognise and change things for the better. There have been improvements at school but only because we have pushed things.
- All the mental health services did is give us a place where we could talk and showed us that there was no magic solution and the only people who could us was ourselves.
- The improvement has been the removal of the stress caused by CAMHS he is coping better but through ourselves and professionals we have had to pay for not through any other help.
- Agree with this but not down to CAMHS- due to time and school and us supporting him better through our own research.
- He is sick between 2-6 times a day from stress. Has diapered regularly. Can’t sleep has nightmares and is soaked in sweat.
- We have received no mental health support.
- Excellent school support, provision from knowledgeable, caring staff.
- The access to CAMHS did not provide support.
- What I have done for he.
- This is with paediatrician what will happen after 19 with no services available.
- Main improvements came as a result of medication for ADHD and CBT for depression and anxiety.
- He has a better understanding of how anxiety affects him on a day to day basis.
- More willing to take responsibility e.g. unloads dishwasher every day but this is more due to the involvement of the Reablement team.
- My daughter is in a better place socially and emotionally but that’s nothing to do with the mental health services. She’s not in full time school so she’s a lot happier.
- If we did not fight for the help he has he would not be like he is now, he would be very ill, constant battle with services.

Question 29: In the last 3 years, what went well when using mental health services?

ASD participant responses:

- Nothing, because mental health services seem unable to do anything relevant to solving the real problems of those with autism (e.g. 85% unemployment, social exclusion, persecution from DWP, unable to access appropriate specialist services ... the list goes on and on). See questions above.
- Nothing went well. At CAMHS we only seen on three occasions and then discharged. We had out appointment for treatment with an Art Psychotherapist and Family Mediator.
- Nothing.
- The speed of being seen was appropriate.
- I was given support after being seen in the sleep clinic as my mental health had a big impact on my sleep. CAMHS would not see me.
- I was able to access material and knowledge with regards to my condition. Attending a Mind Well-Being Centre has been very positive.
- Change of medication which has helped.
- Leaving and going private.
- None.
- Nothing.
- Having an assessment for Aspergers.
- Did not get any help.
- Medication for ADHD symptoms.
- I was put on medication for my Depression.
- They saw me once and told me I wasn't anxious enough for their help.
- My CBT therapist, a psychologist, adapted the therapy for me based on my ASD. She was really good at pointing out that there were benefits to having ASD and therapy was quite successful. My CPN tried to be the only one to see me, and that helped until she upset me one appointment and I am too scared to see her again as she didn't understand how to speak to me.

Parent/Carer responses:

- Hardly anything; clear lack of understanding of autism. Unwillingness to contract specialist help from outside the area. The CCG did and does not want the National Autistic Society to be involved.
- Speed of initial referral from Doctor to assessment.
- Still attempting to access appropriate service.
- Still waiting for assessment.
- Well, we are on the waiting list.
- Nothing.
- Initial support from mental health team superb but fell apart when discharged to car of community mental health team. Felt we were not considered a priority.
- When the diagnosis process started it did conclude very quickly. And we were lucky to have a care plan meeting which was helpful.
- Diagnosis.
- It was an OT who first suggested that my daughter may have autism and not personality disorder which eventually led to diagnosis. They have provided good support to me as a carer and I have had access to family therapy even though my daughter would not agree to attend. This has helped me set better boundaries. Current hospital based keyworker listens to what she says, he has experience of working with people with autism and therefore has a better approach. There is a wellbeing centre locally which has an evening drop in centre staffed by a CPN, if you can take get the person you care for to the centre it is much better than having to go to A&E.
- Everyone we met was compassionate, honest and kind. We've had great support.
- Mum seeing the therapist to give her support that she is an exceptional parent.
- I had a lot of other professionals that would pester CAMHS about how far away her appointment was.
- Diagnosis is what us parents need to move forward not being pushed away from GP or CAMHS so a diagnosis is what we need to be told & written down in black and white.
- We have never been able to access family support as dealing with one member of the family in isolation is no help at all when more than one family member has ASD. Help and assistance in understanding each siblings needs and incorporating strategies that work for the family as a whole and not just the individual.
- Communication between hospital and school.
- Still awaiting follow up.
- Communication with peers.
- Didn't get far as just re reared on again.
- Most visits. The staff listen to my concerns and act on it.
- Nothing.
- It didn't, despite acknowledging his mental health needs, they did not believe they could work with him directly due to his behaviour.
- Nothing!
- The CAMHS team we saw for our initial assessment were helpful and compassionate.
- Not accessing.
- It was a huge disappointment - the relief when we first got referred and the hope we had that we would finally get some real support and help was short lived. They never had the appointments regularly enough and the staff turnover was high meaning no regular psychologist to build a relationship with.

- Nothing - voluntary sector amazing but NHS useless - told unless self harming he would be low on list, but voluntary did preliminary evaluation, made him priority - depressed and potentially vulnerable.
- School were very supportive. Having concerned people suggest autism was a relief. I needed to know his problems weren't down to my failures as a parent. I feel more empowered now.
- Nothing.
- His current doctor listens, but hasn't really reacted as she believes his increased violence is puberty related.
- Supportive CAMHS nurse.
- Medication.
- Not a lot! Poor communication. An acceptance by CAMHS professionals that a 12 month plus delay is okay when a family are in crisis. General poor understanding of strain families are under as a result.
- Still waiting for help and support.
- We got seen for first appointment after just 4 months.
- The advice that we've been given has helped us all to understand and live with Autism better.
- That they did eventually appreciate the severity of the situation and were able to act upon it.
- There was a session of practical strategies for our lad to use That did help.
- We do not use these services as we have never been told what is available to us.
- Nothing.
- Helped to get his EHCP.
- Going private meant we had to wait less for support.
- Not a lot.
- I don't feel we have been supported enough.
- We didn't have a very good experience with the Brookvale service, where as a family members child was treated very different as they didn't have Autism !! ? Mental Health is one thing Autism is a separate issue.
- Nothing they got diagnosed and that was it no more help available signposted to Autism Hampshire.
- The time taken before being given a choices appointment with CAMHS has significantly decreased.
- Nothing.
- A few sessions with a highly experienced clinical psychologist with wide ASD experience.
- The child has gained a better understanding of how they fit into society and what they need to be able to cope well with school life.
- Nothing apart from getting diagnosis but now he has it it's pointless because he received no extra help to someone without autism.
- Eventual diagnosis of ASD.
- Nothing.
- Consistent approach with same consultant.
- Receiving diagnosis meant we were able to access appropriate support at school, medication and external agencies.
- Met some kind and helpful individuals.
- He was diagnosed and given some help in school.
- Already knew the autism history before the first meeting so there was no need to go back to the beginning.
- Nothing!!!!!
- Social communication sessions were very helpful. Moved to home education, which has significantly reduced anxiety.
- Nothing.
- Seeing a psychologist regularly.
- Staff who were and are, receptive to learning about ASC but this should not be a parent's job to educate them! Where's the training for staff. Why no specialised service for people?
- We haven't accessed specific services other than diagnosis.
- Nothing.
- She has someone else other than me to talk to.
- Nothing.
- Felt that he was well understood by the psychiatrist who had an interest in autism.
- After much effort, at last being able to get an expert to give input as a second opinion.
- I went private for the help no local services available.
- It's very slow but eventually got pointed in the right direction.
- The Early Intervention Psychosis Team were a regular point of contact and over time were able to speak to my son for longer periods of time. Sadly when this was improving the decision to withdraw their input was made as he was no longer suffering psychosis and he was refusing to discuss any of the feelings that led to the illness in the first place.
- Nothing, as said they would have left him if it wasn't for us making formal complaints to Hampshire Council.
- Nothing..
- Mental health nurse helped my child have emdr treatment which was very good.

Question 30: What are your ideas of how mental health services and access to them can be improved?

ASD participant responses:

- Help do something to educate society, authorities (business, education, police/law, media, DWP, politicians, etc.) about the needs of those with autism, their strong points, but also the things that cause us to fail and underachieve. Teach them how to support us and be decent to us instead of marginalising, isolating and attempting to destroy us.
- Parents and child's concerns to be taken seriously and not passing the buck to family members or to other services and schools. Have timely access to qualified, knowledgeable professionals who have an understanding of children who have the life-long disability Autism/ASD and the accompanying mental health conditions and know how to assist and treat them. At CAMHS seeing an Art Psychotherapist and Family Mediator at The NHS Sussex Partnership CAMHS service was poor and not suffice. We personally feel that they failed to make the necessary life changes we had hoped for and so desperately needed at that time.
- Better assessments. A service that can actually help. Not being turned away when they have no real idea of the difficulties being faced.
- Continuation of help - everyone is too quick to sign you off.
- Improvement in waiting list times so that the service is accessible to ALL who need it.
- A quicker response to crisis. Response has sometimes been delayed and/or non-existent, especially when I have been suicidal and have asked for help.
- Less waiting times, appropriate services for people with autism, autism specific counselling.
- More money and actually deal and assess people properly before it's too late.
- Don't know.
- Shorter waiting lists for assessments and access to certain teams/departments for therapy.
- Make services more available.
- Bloody hell!! Where do you begin........ Better training for GPs, nurses I understanding & not treating people like they're time wasting idiots.
- The access needs to change. GPs and paediatricians are already quite busy with a number of patients with a varied range of problems. With issues like autism which affects children and their childhood, I think a lot more emphasis should be given to what parents want for their child. There can be a halfway system in which healthcare professionals like physios , occupational therapists, educational psychologists, nutritionist or dietician can be formed as a team to which the parents have access for non-medical problems and they can access at that point if treatment at that point is necessary or not. This way freeing up the doctors time for medical problems not being a clerical conveyor belt system.
- Get a full time permanent Psychiatrist in CAMHS Basingstoke, Not just diagnose, medicate and leave, need help to learn to deal with issues and live a better life.
- Have regular appointments with a professional in the service to keep updates on personal situations, give help with anything and generally be a mentor.
- Help people before they reach crisis point.
- Why.do I need to be assisted so many times. Why do you not more effort into treatment required.
- CPNs and care coordinators need better education about ASD. There should also be options for people to be able to get in touch with CMHT by text or email. Phoning for help was extremely hard. Giving more information on what will help would help ease the anxiety around the unknown especially prior to initial assessment. Photos of the building and/or some information about the person you would be seeing would help too.

Parent/Carer responses:

- Not all online, wearing when can't access it. Funding cuts.
- Need for specialist department at local level.
- Funding?
- Parents and professionals who know the person being listened to.
- Employ more people.
- Shorter waiting times for initial consultation and quicker sending out of diagnosis reports.
- Access to them would be good. So that you do not have to get to the point where your child is attempting suicide on a regular basis before you get help. And understanding that an autism diagnosis does not preclude someone from being able to benefit from mental health services. An understanding of the impact upon the family and support for them too.
- Better training for all staff and more specialist staff but also better signposting/support for parent/carers and an understanding of how they feel.
- Continuity and communication between various professionals particularly on handover need to be more efficient.
- Professionals need to realise that after one meeting, they do not know the child/ young adult best. They must listen to parents.
- It must be a nightmare trying to sort out these issues. I feel that the school has too much say in whether any intervention is needed. I tried to go through my GP and they referred him with no success because at that time the system was under review. So far my son has wasted 3 years of education and continues to be in the wrong system at mainstream school. Some days I really feel that he should be at home but I feel torn that he should be at school too.
- Information given from GP, or consultant. Team to contact on diagnosis to see if you need help.
- Training on autism so that staff can recognise this and also work in a different way e.g. stop expecting attendance at groups. Allow time for person to process information and don't overload them. More flexibility in how to communicate with people e.g. using text or email when talking by phone is difficult. Joint working between autism and mental health teams.
- More funding. More staff. More general awareness of mental health problems via marketing/etc.

- A family like ours should have easier access, this weekend we dealt with my son saying he wanted to kill his epilepsy and he hates his life... But he needs non talking therapy options.
- You should be seen within 2 weeks for a chat and initial pre-assessment. They should do assessments for lots of different mental health problems as it seems they like diagnosing autism and ADHD like water.
- Less waiting lists more understanding in schools GP surgery's nursery's etc. more symptoms charts in the above places, more funding to help children and adults get a diagnosis CAMHS to be more understanding and see consultants in CAMHS not just nurses. Don't just shut people out when they need help and understanding.
- Listen to the parents more. We are not making things up. We know what works for our families and what can be achieved in the home environment. We are not perfect but parenting ASD children is challenging, tiring and not enough hours in the day. But these children are unique, quirky, intelligent and deserve the opportunity to reach their full potential the road is just a bit more challenging.
- Waiting times.
- Not having to wait long to be seen. Extra support or being pointed in right direction for help.
- Carer links through NHS helplines. Specialist Asperger training for LD support teams.
- More appointments.
- More, more, more.
- Change the criteria back to what is was under family guidance my older two got a lot more help but none of them are getting any help since turning 18.
- More staff. More access for people with concerns about needing assessments.
- Widen the range of who they will help and not dismiss a child in distress because they are autistic.
- Recognition of the aspects of autism that affect emotional wellbeing and provide support/help. There is no short fix and therefore services aren't interested. I was told that my son's anxiety, violence, self harm, sleep problems, intrusive thoughts and hearing voices were because of autism and therefore he couldn't access services.
- Waiting times cut, we are currently 41 weeks into a possible 70 week wait for an assessment for ASD.
- More awareness.
- Mental health services should be a priority as it seems that this area is getting worse - access should be 24/7 as in reality crisis moments normally happen at of normal office hours. Mental health services should invest in cafés where families and young adults can go and meet others in similar situations and find help in each other.
- Request should give immediate / near immediate evaluation so priority can be set accordingly. Proactive rather than reactive support - help before start harming self or others or becoming incapable.
- There needs to be autism specific help and need to listen to the parents, not make them feel inadequate failures.
- The diagnosis process should be sped up. Information is power.
- Actually offer some help solutions strategies.
- Home visits, and 24 hr helpline would be so helpful.
- Offer a more specialised service for children with autism. More appointments.
- When we arrived for our one appointment the nurse entered the room and announced that we were to move to another room - she did not introduce herself to my son - (my reports prior to the meeting detailed high level anxiety in new unfamiliar situations especially with people he didn't know) My son was very anxious and was stuck to the chair in the waiting room - I said 'oh sorry - I didn't catch your name and at that point she realised that she needed to introduce herself. She spoke in a more appropriate way to my son. He was still reluctant to leave the waiting room so she tried to tempt him by offering him a bourbon biscuit if he managed to go to the other room. I was again a little surprised at this in view of the other reason for us attending CAMHS was his reluctance to eat, especially in the company of strangers. I feel it would be so helpful if the professional had a good understanding of the needs of each person visiting for an appointment before starting the session. In our situation towards the end of the session after my son had started to feel a little more comfortable he was asked if CAMHS was something he would be interested in attending - he said yes, and then literally 2 minutes later the nurse said that she was sorry but due to the fact that he already had a diagnosis of ASC/Aspergers - he could not be helped under the NHS for his anxiety or eating issues as these were not mental health issues they were as a result of his diagnosed condition. I have to say I was floored, but as my son was with me and I am totally aware and understanding of his sensitive nature, I simply said that this surprised me and I asked who could help us with his anxiety and eating issues - The nurse asked if I had heard of the National Autistic Society !!! It is possible it was not totally appropriate for my son who was just 13 at the time to be present for the entire meeting. As far as I understand my son still has mental health issues, always has and will be with him always but he does need some help and support.
- I do not believe the opt in appointment system works with this client base as in my experience they struggle to keep appointments due to the fluctuation of their moods, i.e. some days they are happy to engage with others and some days not. If an appointment is missed I found that they were then taken off the list. There must be a better system to get to see clients that struggle to engage.
- Much better communication, better links with other services, more staff, better training.
- Not had help yet from this service.
- Make them more accessible.
- Waiting list too long, lack of different ways to approach different sorts of people (one box fits all approach). Lack of use of facilities that may make for providing a successful experience.
- We have received excellent support from the Mustard Seed Autism trust. Help for family and he is beginning a course with them to help his anxiety and give him strategies for managing it.
- Every time we have been we have seen a different person. Need more continuity.
- More funding.
- For us, this is too early to say.

- I do appreciate that there is a limit to budgets but this YP family have tried to access this service previously and got nowhere. Transition to secondary has obviously made things worse for her and her mental health has deteriorated to the point of crisis this week. It would be more helpful if it was dealt with before it reached this stage. The family feel very disillusioned with the service and badly let down. The YP herself said that she was only seen once previously, told the professional everything and that person then left and she disappeared back into the system. This is simply not good enough.
- Drop in clinic for young adults who have ASD counselling/ therapy for parents.
- Letting people know what is available to them and how to access them.
- For them to listen to everyone evolved with the child and to help that child not keep putting them on the waiting list.
- Better access to service less cutbacks.
- Tailored services for people on the spectrum.
- An actual transition from CAMHS to adult services for ANYONE being supported by CAMHS should be in place, and it should not been an even bigger nightmare for parents to run around sorting out. Do you actually know how much of a nightmare our lives are already, without having to run around trying to get support?
- Accessible 24/7.
- The service should be more widely available in schools/college. Also more training also in schools/college to spot mental health issues
- If they have siblings then you should be able to get them seen as well.
- More ideas needed for how to support children in the meantime whilst the lengthy process of a diagnosis of Autism is being sought and also once the diagnosis is received.
- Better training, easier access, more intense and better therapies deliver to children, that will have a great effect on their well-being and prevent significant reliance when entering adulthood.
- An acknowledged that anyone with ASD still needs mental health support. This is definitely not happening on the IOW.
- Too hard to get support. Thresholds are too high - children are needing help and getting declined. More resources.
- Spreading awareness. Notices on library/supermarket boards. Leaflets everywhere. TV/radio advertising. Local groups - Mencap/Mind etc. Someone coming to home every month to check all is ok or if help is needed in any area.
- Access to someone at the GP surgery who can help or direct appropriately.
- More doctors have only seen a doctor once.
- Smooth transition from child to adult services MUST HAPPEN. IT doesn’t exist.
- Advertise widely. It should be the same as for physical health. Everybody knows how to access GP hardly anyone knows anything about mental health. Simplify systems so they don’t confuse people. More work done to reduce prejudice/ ignorance. Promote acceptance of difference in the community starting in schools working up. Properly fund the entire system so that people can have a named worker to guide them through and there are beds available. Prevention is better than cure. Why just fire fight with acute cases. More work done prior to crisis point would definitely help.
- Referring to other support services if they unable help or the delays are too long. Increase funding. Have autism specialists.
- Get more funding, more training, expand department.
- To give more help and advice.
- Don’t know if you can access them other than going through the GP.
- For the service we had through a private psychiatrist and therapist be available on the NHS, free or significantly cheaper. Very good experience of private therapy but very poor for CAMHS.
- When someone is diagnosed with autism they should be auto referred to a mental health services caseworker who will not strike you off your books but will be available on an appointment basis when the need is required.
- Earlier intervention and better monitoring.
- Don’t leave it until they reach crisis. We were told to come back only when that occurred.
- There MUST be fully trained, caring and understanding staff available. Doctors need to be formed about ASC. Some psychiatrists are in the dark and as a result, wrong diagnoses are given with frequent harmful outcomes, e.g. Personality disorder. Why don’t we have a designated autism service with staff who truly wish to help and understand how mental health issues impact on the person with autism. Why don’t we have a clearly defined autism pathway within mental health services? There is one for learning disabilities service but it for adults with autism who are in or need to be seen within mental health services. Often these individuals suffer from being misunderstood, misdiagnosed and sadly, given inappropriate treatments and interventions. Access needs to be easier. I take exception to criteria to MH services having ASC and/or Aspergers as an exclusion criteria unless a co-morbid MH condition is present and serious! Where is the preventative care and input? Referrals to Primary crew and IAPT if fruitless due to the lack of knowledge of autism practitioners have. They do not have the required skill set.
- There needs to be a lower threshold for access, it should be that children have to be at crisis point before they can access services. We would love extra help on managing anxiety for example, as if we have good strategies, this would hopefully prevent issues becoming worse.
- Not always saying it is their autism and so nothing can be done. Looking beyond the autism and treating the problems.
- Ask parents orders on involved what sort of individual help they need. GP should be able to access right services as they are usually first port of call.
- There needs to be more support like the support he got from the Reablement team. They taught him how to be more independent e.g. using a bus, doing laundry, making a weekly timetable for himself. He will not accept this kind of help from his mum! It has to be someone neutral.
- Get a dedicated service for autism!!! Or at least provide a decent level of training so we are not told “we don’t understand autism”!!
- I have no help from the local services.

- You need specialists in certain fields to offer actual help rather than airy fairy advice from the internet or a few books they've studied. I feel like I could teach these people more than they can teach me. We were offered a parenting course on autism when I asked for help with my sons tics.
- Listen to the parents more rather than telling us it's our fault. After 4 years of telling them she needs help they then decided she's autistic we knew all along.
- They need more staff for more regular appointments and support.
- Autism training above all else and not just a half day. I think it should be a compulsory module. It is not uncommon for people with autism to develop mental health problems so I think it is really important for the profession to have appropriate training or they are in my view not competent to support people with autism and a lack of knowledge could impact very negatively on the progress of the person they are supporting. Funding so that the services are more readily accessible and the quality of ongoing support for people with autism is better. i.e. day services, opportunities to go out, build confidence, engage socially. Family support to enable the carers to care and look after their own physical and mental health.
- Listen more, don't fob people off because it will cost money, not enough people trained in autism which is the key problem, we keep being told there's no money for training.
- I think a plan needs to be put together that GPs can access which shows the GP how and what to do when an autistic person visits them for help with a mental health issue. A specialist autistic mental health team with specially trained workers on how autistic people experience mental health needs to be set up that is separate to the neuro-typical service. It would incorporate the two issues as a whole rather than two separate issues, this would help the person with autism to feel more understood and therefore more supported.
- Put more money into the services so they can help more than just a few people.
- Stop putting everything down to just their autism listen to parents.
- Get more people in to work with the children and family's reduce cancellations which would reduce stress for parents.