

DHSC National Autism Strategy Consultation: Results

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1. Background

Between 29 April and 10 June 2022, we ran a public consultation to ask our Island's autistic community what they need us to include in our first National Autism Strategy. We wanted to find out about any current gaps in services or support, and what the community's priorities for improvement are. We asked a range of questions about autistic people's experiences, needs, and values, to give us a better understanding of how we can help our autistic community to flourish.

In total, 392 people responded to our consultation. These were a mix of autistic people, their family, friends, and carers, and professionals from various fields.

Figure 1. Bar chart of all respondents

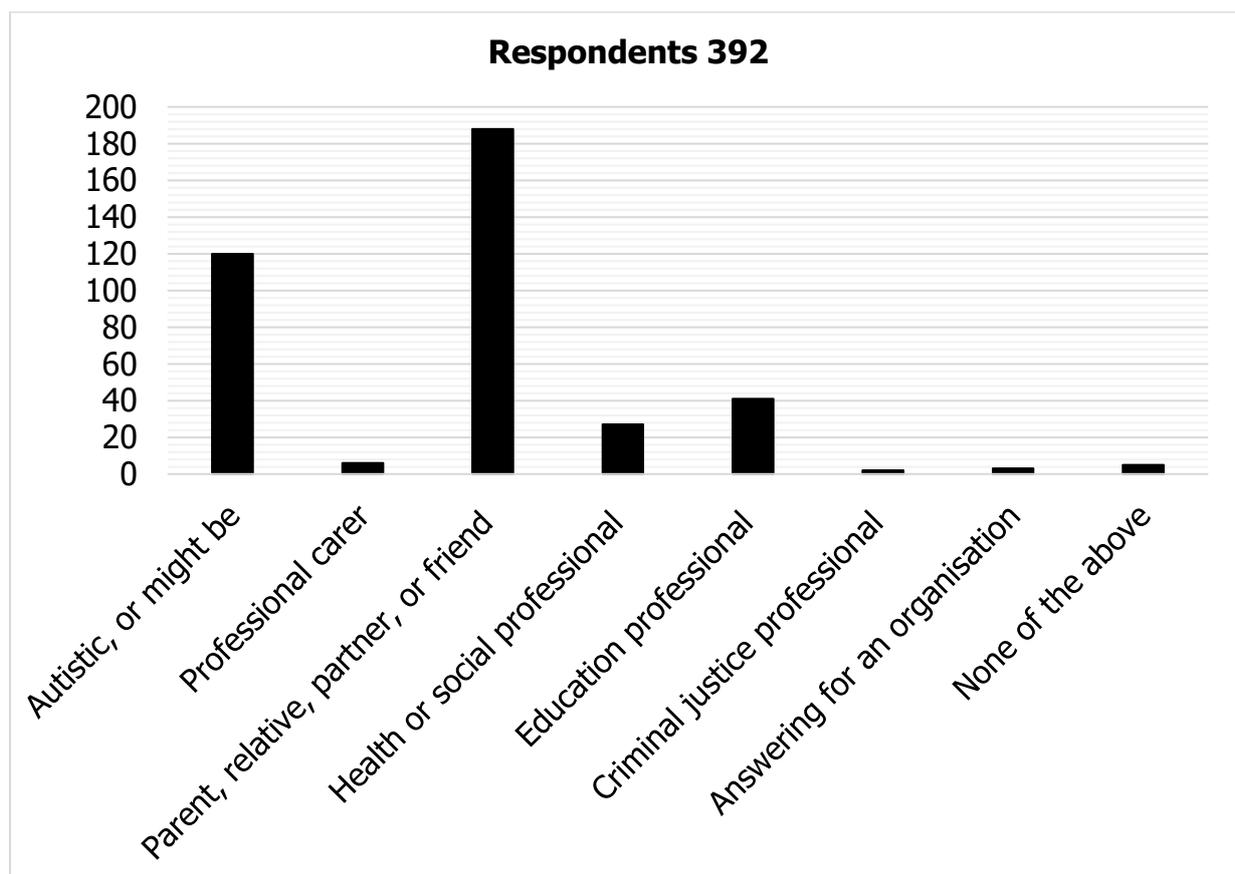


Figure 1 shows 120 people were autistic, or thought they might be autistic, 188 were parents, relatives, partners or friends of autistic people, 6 were carers answering on behalf of an autistic person, 41 were education professionals, 27 were health or social

care professionals, 2 were criminal justice professionals, 3 were answering on behalf of an organisation, and 5 were none of the above.

The consultation was split into two parts. In Part 1, we wanted to hear about what life is like for autistic people in the Isle of Man – this part of the consultation was only for autistic people and their family, friends and carers. In Part 2, we asked everyone (including professionals and other interested parties) what they thought would improve support for our Island’s autistic community.

2. Listening to our autistic community

In Part 1, we asked our autistic respondents to tell us about their own experiences, and we asked family, friends and carers to tell us about the experiences of the autistic people they support. We call responses from autistic people ‘direct responses’, and responses from their parents, relatives, partners, friends or carers ‘proxy responses’. Wherever possible, we will distinguish between direct and proxy responses by showing them as different colours in our bar charts.

Figure 2. Bar chart of age

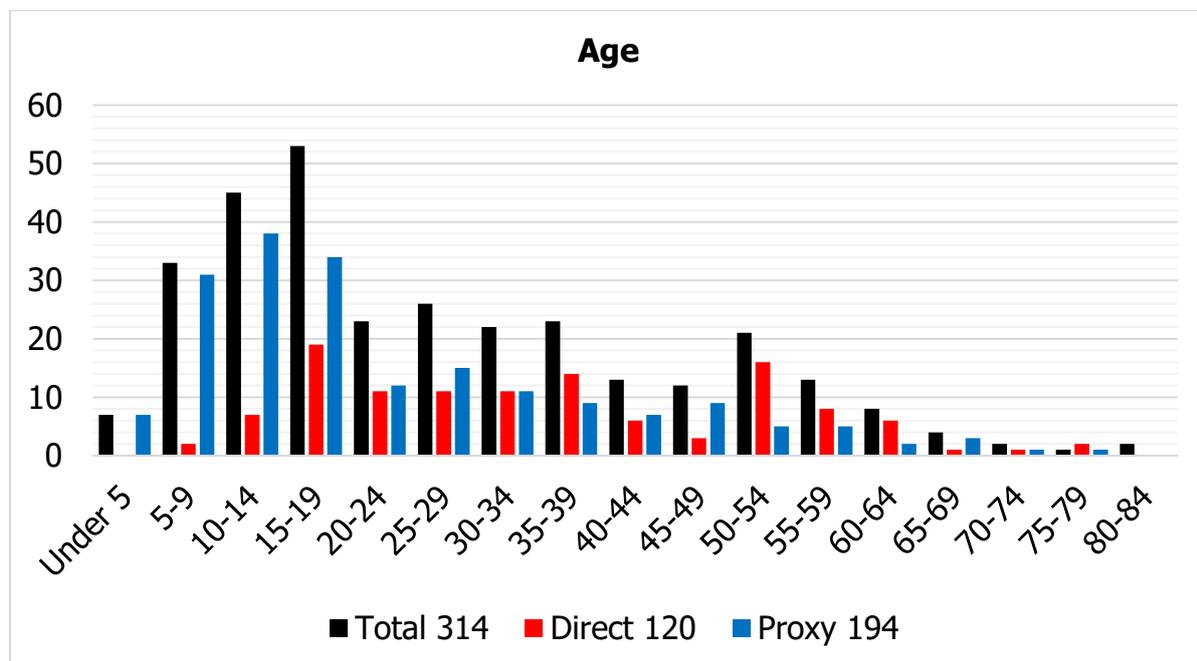


Figure 2 shows that people represented in this consultation ranged from under 5 to 84 years old. The majority, 154 people, were between the ages of 5 and 24.

Figure 3. Bar chart of gender identity

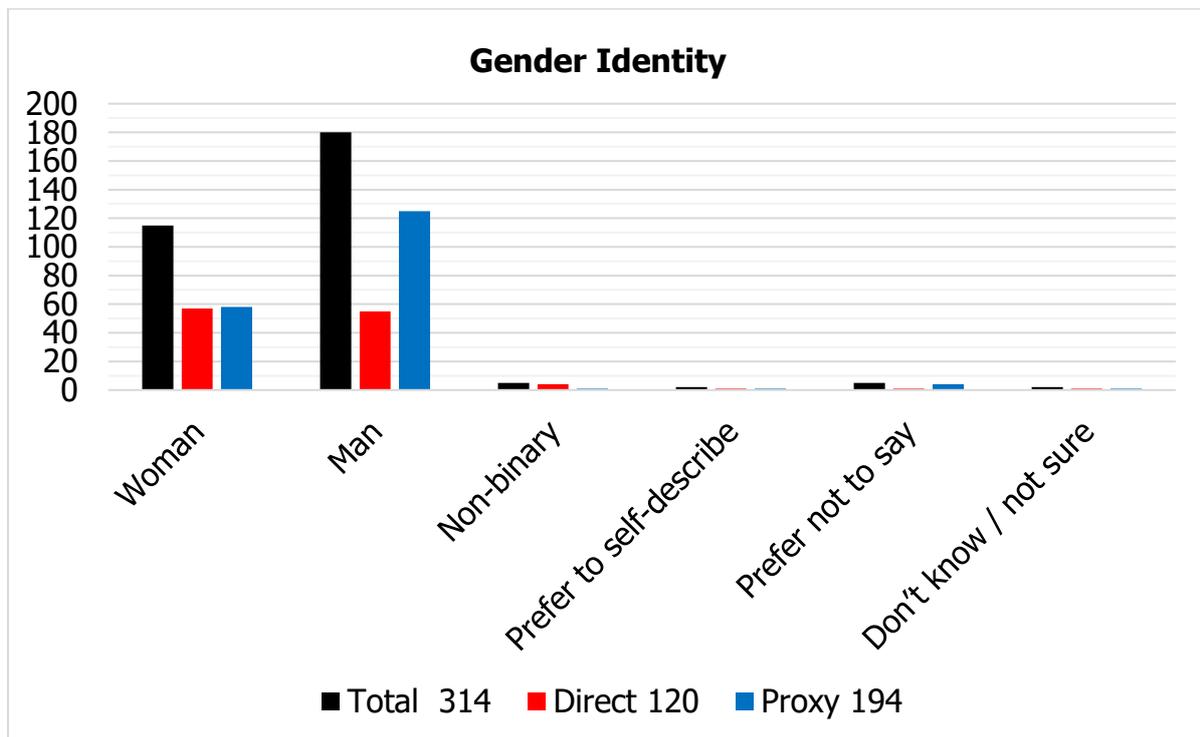


Figure 3 shows 57% of responses were from, or on behalf of, autistic men and boys, while 37% were from, or on behalf of, autistic women and girls. Five respondents were non-binary, 2 preferred to self-describe, and 5 chose not to answer.

We asked people about their experiences of referral and diagnosis, what support services they receive, and which things can help to promote acceptance and inclusion.

We asked a mix of closed questions (ones with a list of answers to pick from) and open questions (ones which let people write in their own answers).

In total, answers to the open questions amounted to 195 pages of text. We analysed this text to pick out recurring themes in people's answers, and then we counted the total number of comments relating to each theme. This let us see which issues are causing the greatest concern for our autistic community.

Figure 4. Pie chart of themes

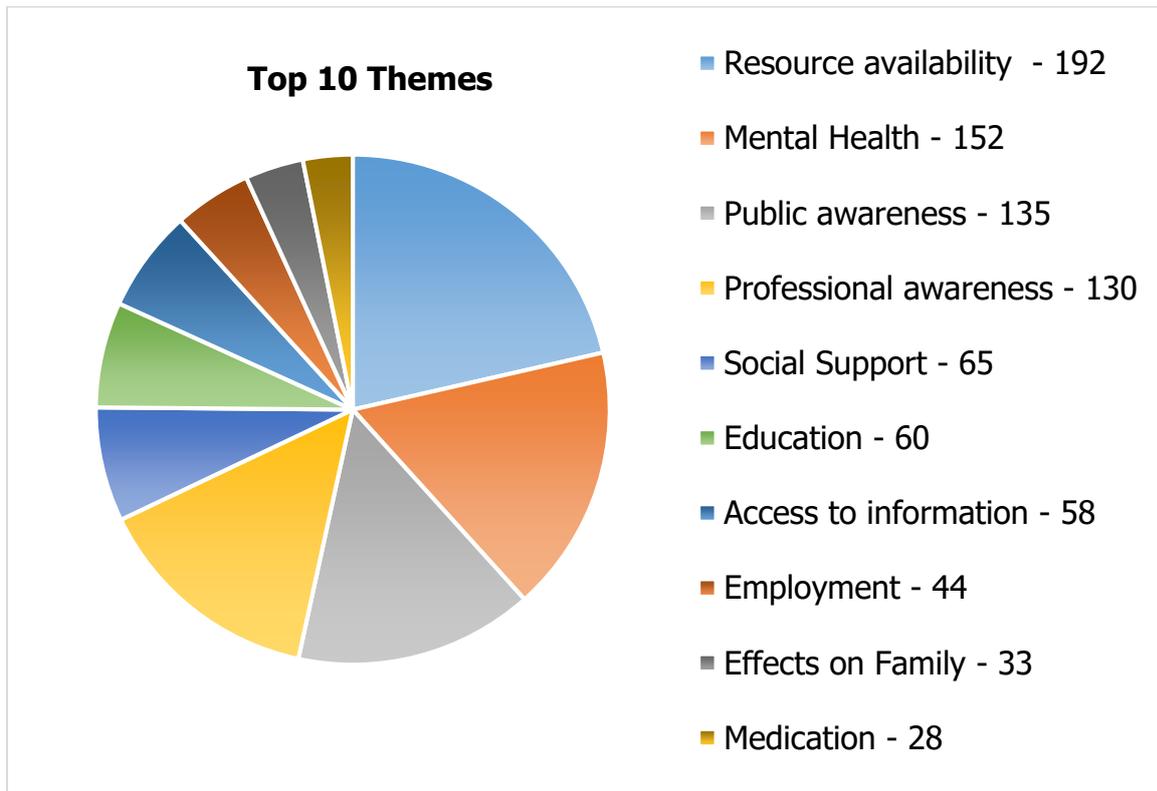
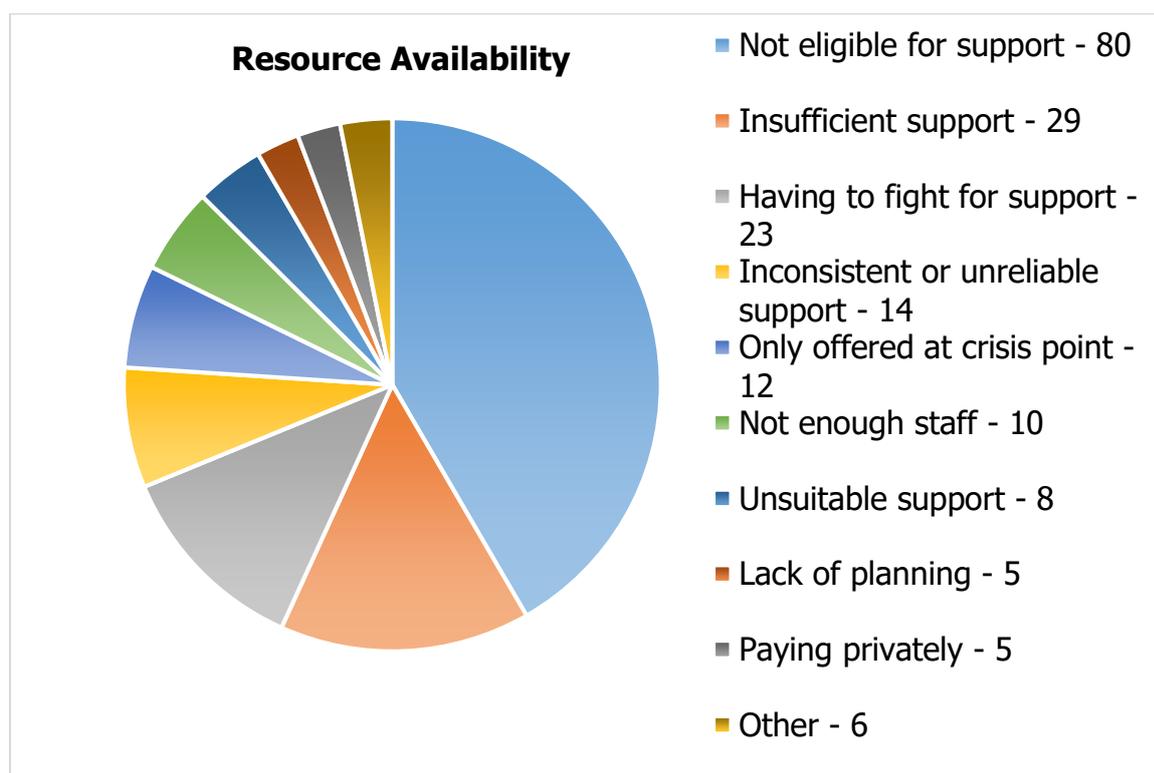


Figure 4 shows the 10 biggest issues which emerged from our consultation, measured by total comment count. The issue with the highest number of comments was resource availability, followed by mental health, public awareness, awareness among professionals, education, social support, access to information, employment, effects on family, and medication.

2.1. Resource availability

Lack of resources was the issue people commented on most frequently in the consultation. There were 192 separate comments about people not being able to get enough, or the right kind or support. Figure 5 shows the sub-themes people raised about the issue of resource availability.

Figure 5: Pie chart of sub-themes for resource availability



The largest number of comments were about people not being eligible to access any kind of services or support. A smaller but still significant group told us that the support they get is not sufficient to meet their needs. Other recurring themes included having to fight for access to support, inconsistent or unreliable support, and hitting a crisis point before any support is offered.

2.1.1. Diagnosis

Many adults told us they were not able to get a diagnosis for suspected autism without paying privately. As figure 6 shows, of the 308 people who answered part 1 of this consultation, 57% said they (or the person they support) have a formal diagnosis of autism or Asperger's syndrome, 16% said they suspect they are autistic and are waiting for referral or diagnosis, 14% said they suspect they are autistic but haven't asked for referral or diagnosis, 5% weren't sure if they had a diagnosis, and 8% chose not to answer.

Figure 6: Bar chart for number of people with a formal diagnosis

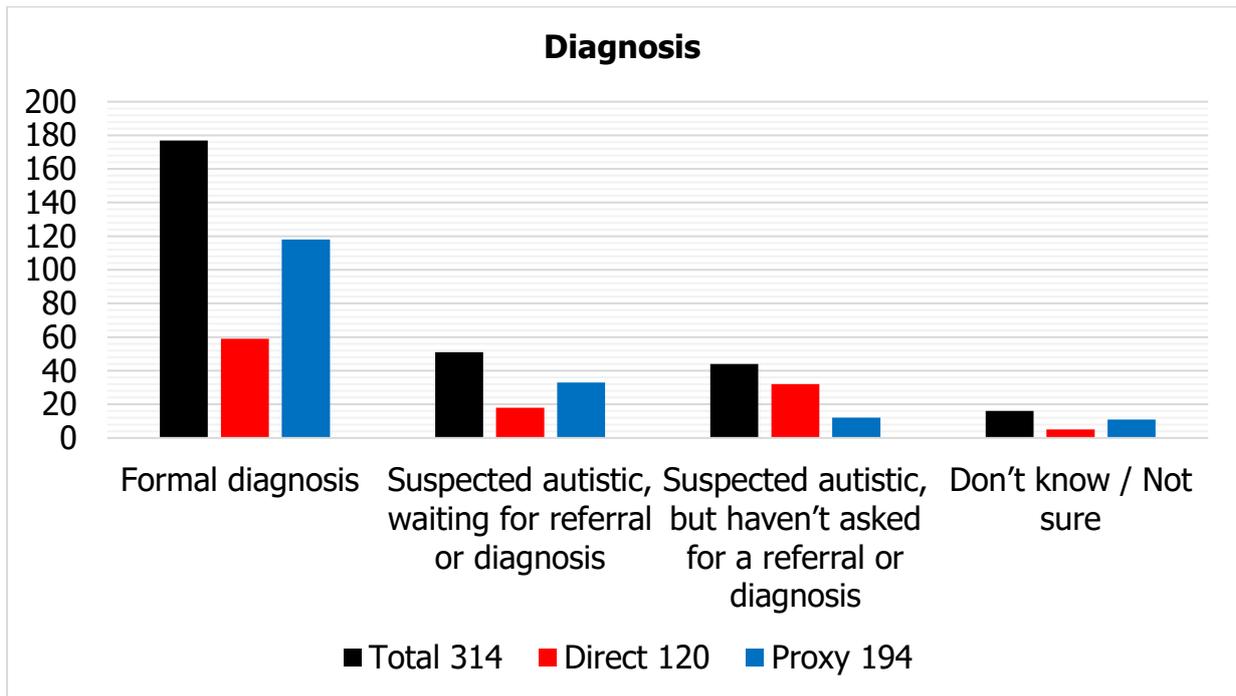
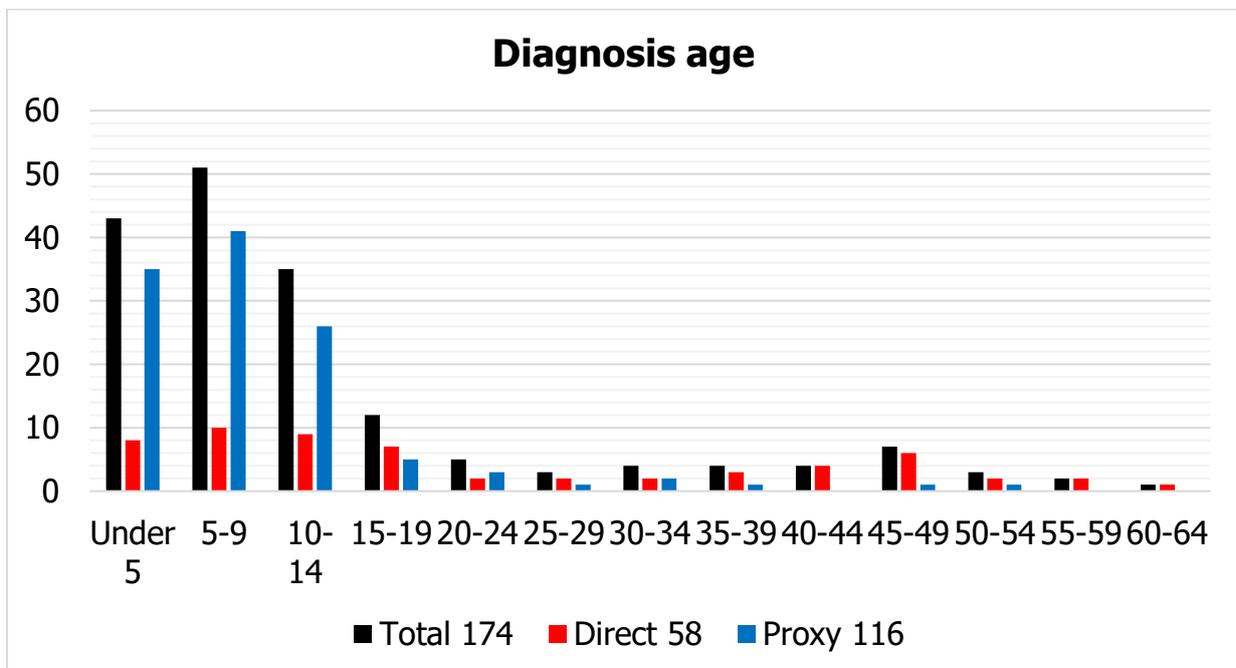


Figure 7 shows the age at which people received their formal diagnosis – a large majority of people with a diagnosis received it during childhood or adolescence.

Figure 7: Bar chart of age at diagnosis



Some of the things people told us:

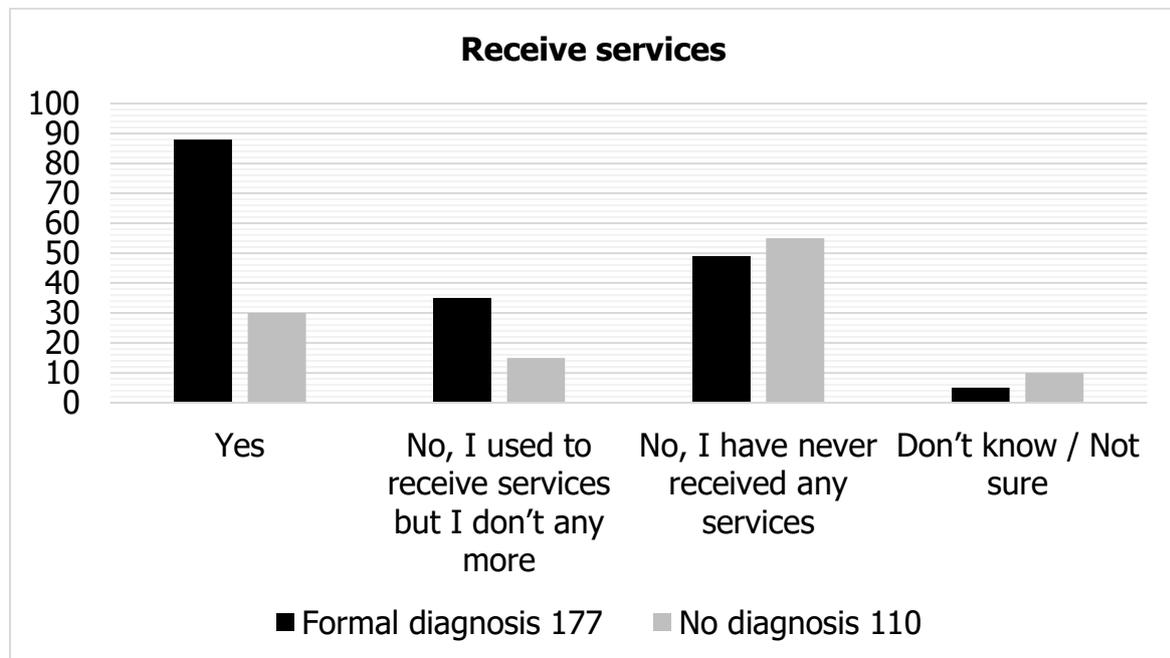
“GP referred me to adult mental health...but the referral was declined”.

“There is no chance to get a diagnosis in my age group”.

“Multiple doctors told me there was no pathway for diagnosis as an adult”.

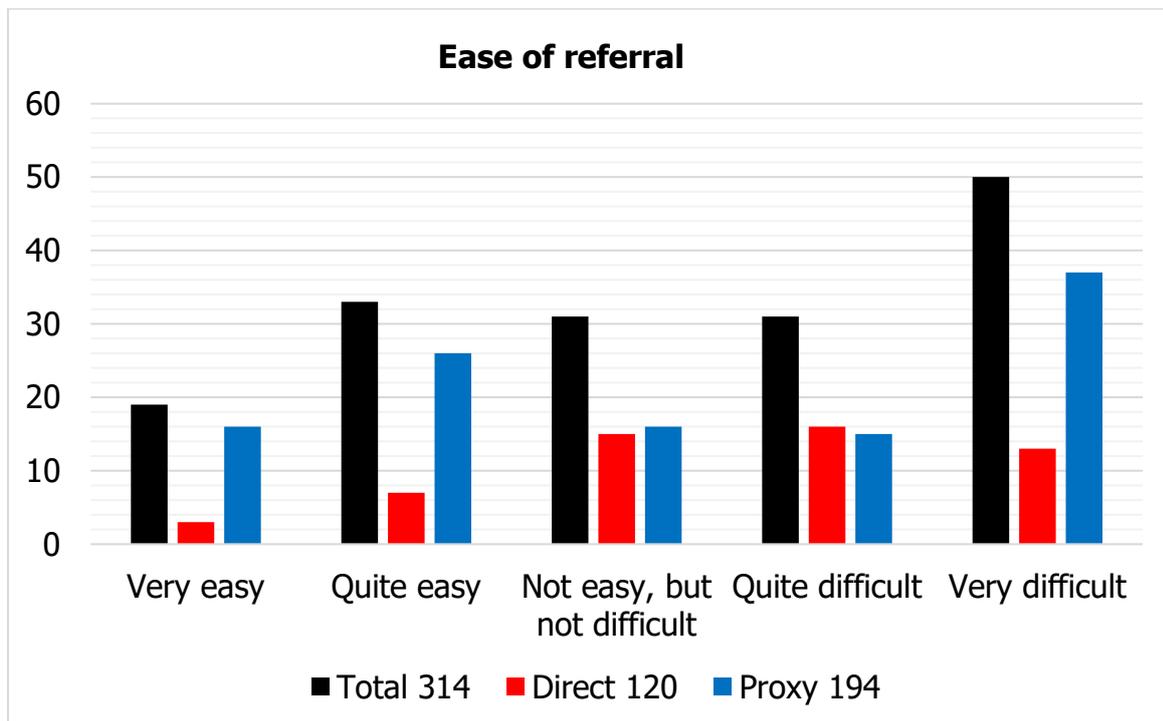
People told us that not having a formal diagnosis of autism or Asperger’s Syndrome makes it much harder to access any services or support. Figure 8 shows that the majority of people who receive some kind of support service have a formal diagnosis, and the majority of people without a formal diagnosis receive no support.

Figure 8. Bar chart of people who receive services, diagnosed vs. undiagnosed



Of those people who do have a formal diagnosis, the majority, 46%, told us that the experience of getting a referral had been very difficult or quite difficult, as shown in Figure 9. Only 29% of people had found it easy or very easy, 18% told us it had not been easy or difficult, and 7% chose not to answer.

Figure 9. Bar chart of ease of getting a referral



When asked who had referred them for diagnosis, 28% said it was a GP, 21% said it was a school or Educational Psychologist, 18% said mental health service, 10% said a pre-school or nursery. A small number of people said they had been referred by a health visitor, social worker, private specialist, or speech and language therapist.

2.1.2. Support

Having a diagnosis doesn't guarantee support – nearly half of people with a diagnosis told us they don't receive any support services (see Figure 8).

Many people told us they are not eligible for any support following their diagnosis because they do not have a learning disability (defined as an IQ below 70).

Some of the things people told us:

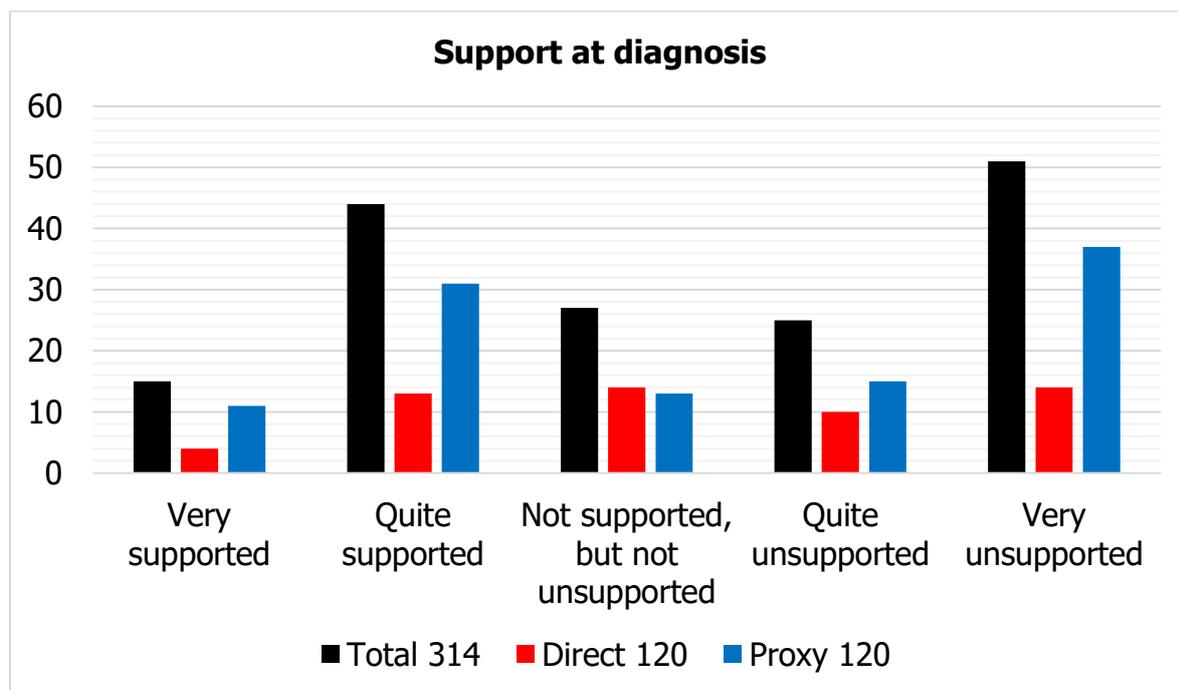
"Upon receiving my diagnosis I was discharged from the mental health service".

"Nothing happens after the diagnosis. As an adult you're just given a pamphlet and off you go to figure it out for yourself".

"No follow-up and no ongoing support".

Figure 10 shows that 43% of people who have a diagnosis felt very unsupported or quite unsupported following their diagnosis; 33% said they felt quite supported or very supported; 15% said they had felt neither supported nor unsupported; and 8% of respondents chose not to answer.

Figure 10. Bar chart of feeling supported after diagnosis



People who did receive support during childhood or adolescence told us it stopped abruptly at adulthood.

“Since he hit 18 no one has checked up on him, no contact from any departments or strategies to help him get employment”.

People also told us that service cutbacks meant they were no longer receiving any support, or as much support as they used to.

“We feel very alone”.

We asked people which things they feel they need more support with. Figure 11 shows 52% of people said they needed more support with mental health, 40% need more support with social activities, and 37% need more support with education. Many people also said they need more peer support, more sports and leisure activities, and more support with paper work and employment.

Figure 11. Bar chart of unmet needs

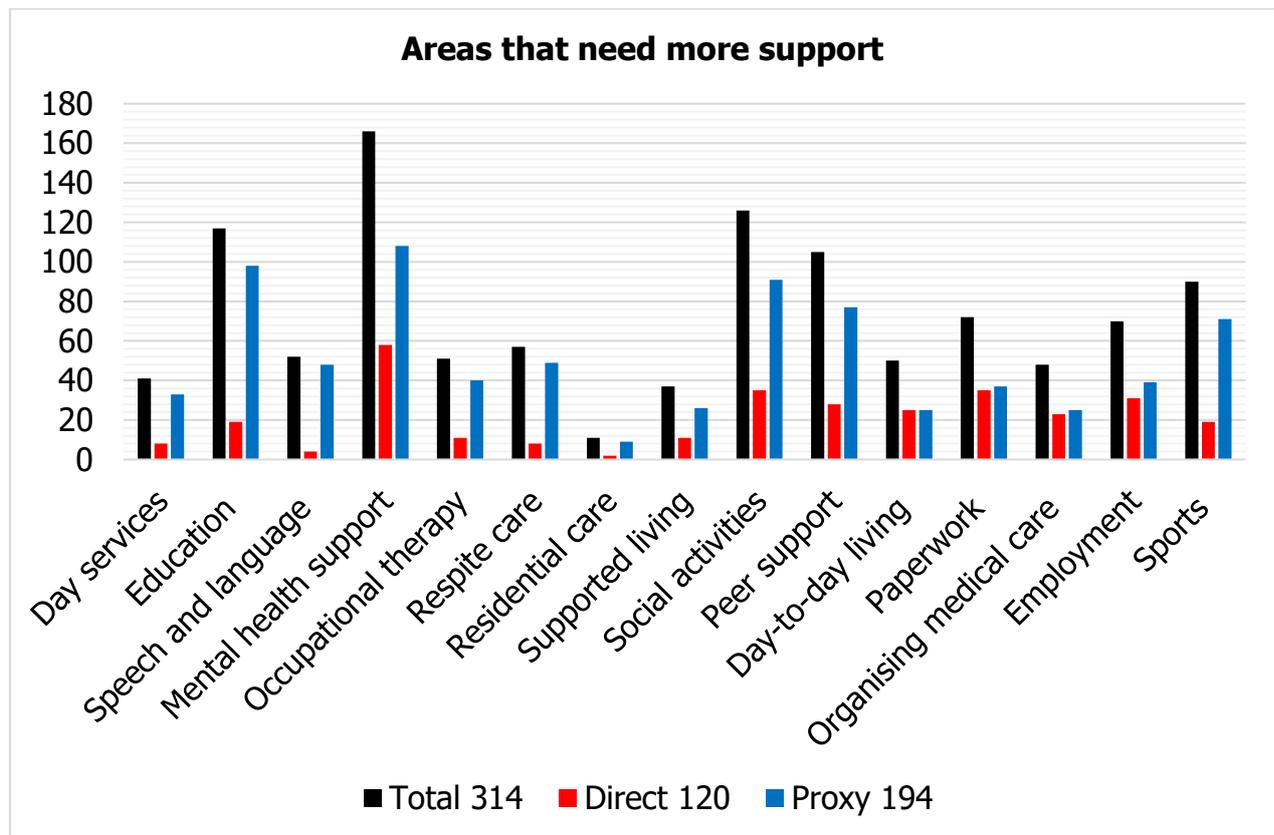
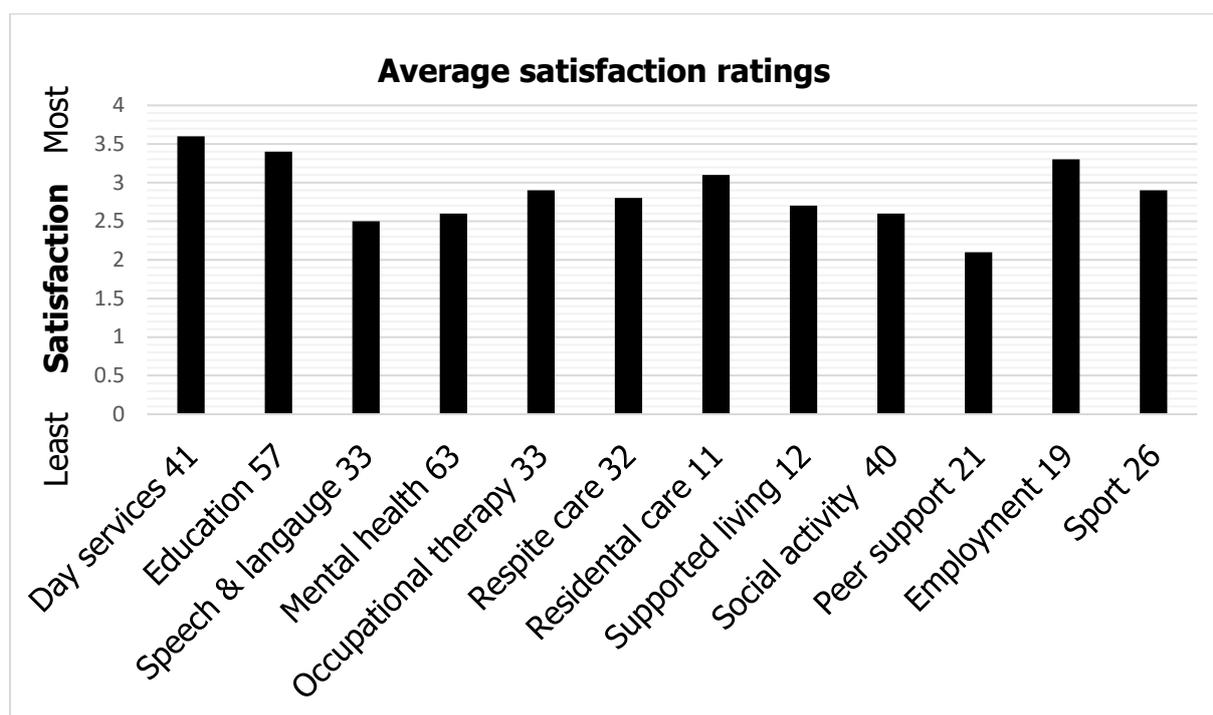


Figure 12 shows the average satisfaction rating given by those who do receive support services. The three services with the highest average satisfaction ratings were day services, education support, and employment support. The three lowest ratings were for peer support, speech and language therapy, and mental health services.

80 people told us they receive support from more than one team or organisation. When asked whether these different teams work together well, 34% said yes, 20% said no, and 46% said they weren't sure.

Figure 12. Bar chart of satisfaction ratings by service type



2.1.3. Other sub-themes in resource availability

People told us that they have to fight for support, and that asking for help can feel like a battle.

“We have to fight all the time to get anywhere”.

“Everything is a fight, you fight for support, for help, to be taken seriously”.

Some people who do receive support told us this support can be inconsistent or unreliable, particularly in school holidays. Cancelling or moving appointments, particularly for respite care creates problems for some families, and high staff turnover can be distressing for people receiving support.

“I don’t like it when staff keep leaving as I find it difficult to trust new people”.

People also told us they feel they have to hit a crisis point before any help will be offered.

“I was told by my GP to come back when I was suicidal, until then there were no options for me”.

“Prevent people from reaching ‘rock bottom’ before someone will help”.

Some people pointed to a lack of staff as a problem in getting the right kind of support, particularly in areas like speech and language therapy, mental health, and occupational therapy.

“IOM Government have no resources to support the amazing front line staff”.

For some people, the support offered has seemed unsuitable or inappropriate.

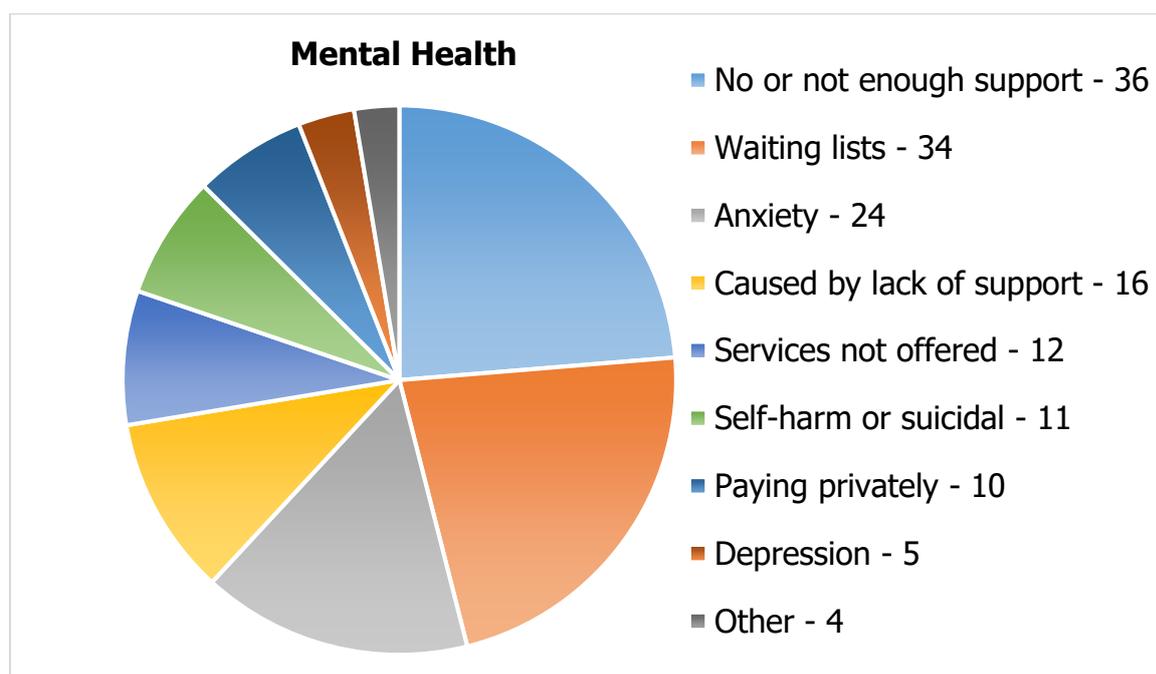
“I was offered free gym sessions at the NSC but didn’t feel able to go due to my social anxiety”.

Others told us they are concerned about a lack of long-term planning in establishing support needs. Some people told us they are paying for support services privately. Others expressed worries about medical support pathways for conditions which can occur alongside autism, such as epilepsy.

2.2. Mental health

The second most mentioned issue in this consultation was mental health. There were 152 separate comments about mental health, or mental health services. Figure 13 shows a breakdown of the sub-themes people told us about in relation to mental health. A lack of support and long waiting times were the two biggest concerns expressed. Many people mentioned experiences of anxiety, or other mental health problems caused by feeling unsupported. Other sub-themes included a lack of specific therapies on Island, worries about self-harm and suicide, and experiences of depression.

Figure 13. Pie chart of sub-themes for mental health



As Figure 11 showed, mental health support was the biggest area of unmet need identified by people answering this consultation. People who said they can't access enough support told us they feel let down and left without frequent contact.

"In general mental health services give the impression that they do not want to help high functioning adult autistics and view them as a nuisance wasting their time".

"Autistic people have high rates of mental illness and weak support networks, but therapy designed for neurotypicals is often less effective".

"CAHMS have been excellent but are so underfunded and understaffed".

Waiting times are an issue for many people, particularly in relation to the Child and Adolescent Mental Health Service (CAMHS). People told us they had faced wait times as long as 2 years, and had struggled to cope without support.

"If CAMHS had given us support at the right time, we would have had the support from school required to keep her there. Unfortunately and sadly it was too late".

"The entire thing is a nightmare. Huge waiting times".

Anxiety is a clear mental health concern for the autistic community, with 24 separate mentions of people struggling with anxiety. Mental health problems arising from a lack of support for autistic people were mentioned 16 times, with people telling us:

“I can’t work due to mental health issues arising in part from the lack of understanding and support for autism”.

“Only received support for mental health not autism. If the autism help had been available, my mental health would not have declined”.

“I lost my dream job because of mental illness, and it turned out I was only struggling with mental illness because I was undiagnosed autistic”.

“Some days I did not know if I was going to find her alive in the morning”.

People told us they are unable to access specific forms of support on Island, particularly talking therapies such as Dialectical Behaviour Therapy (DBT), and art, animal or play therapies. Some people told us they are paying privately for mental health services.

2.3. Public awareness

The third most mentioned issue in the consultation was a lack of autism awareness among the general population of the Isle of Man, with 135 separate comments. As Figure 14 shows, the overwhelming majority of comments (121) related to misperceptions or negative attitudes encountered in public.

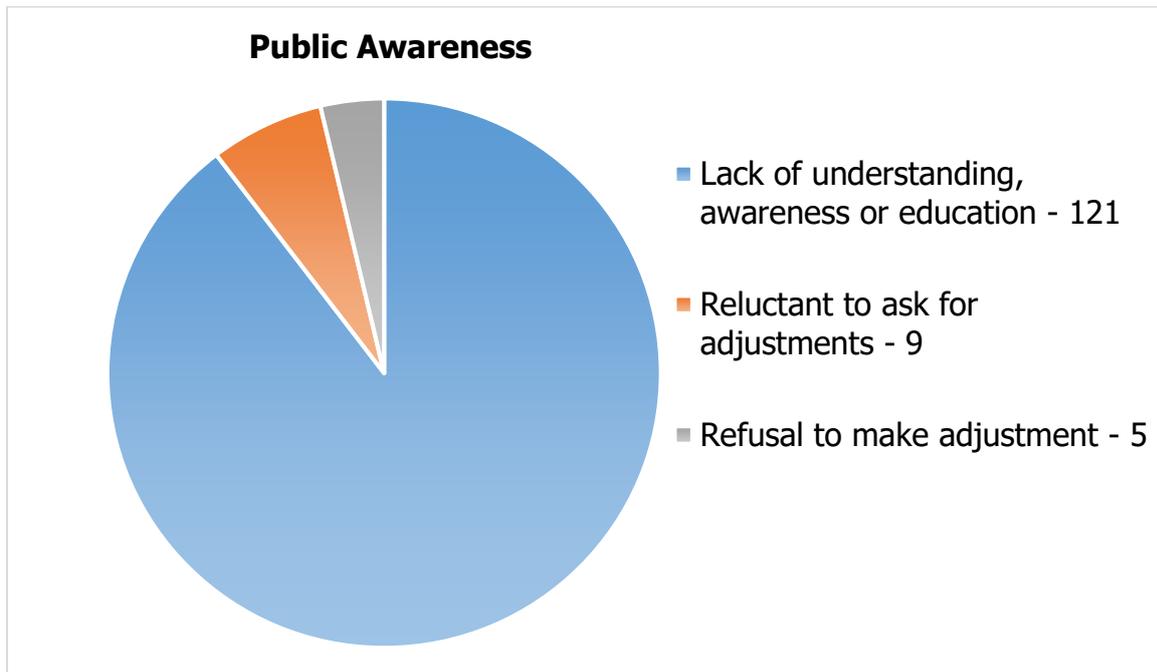
People told us about their experiences of being judged or misunderstood in public:

“People are very quick to stare”.

“Others find it difficult to take me seriously and understand my difficulties”.

“People tut over the noises my son makes”.

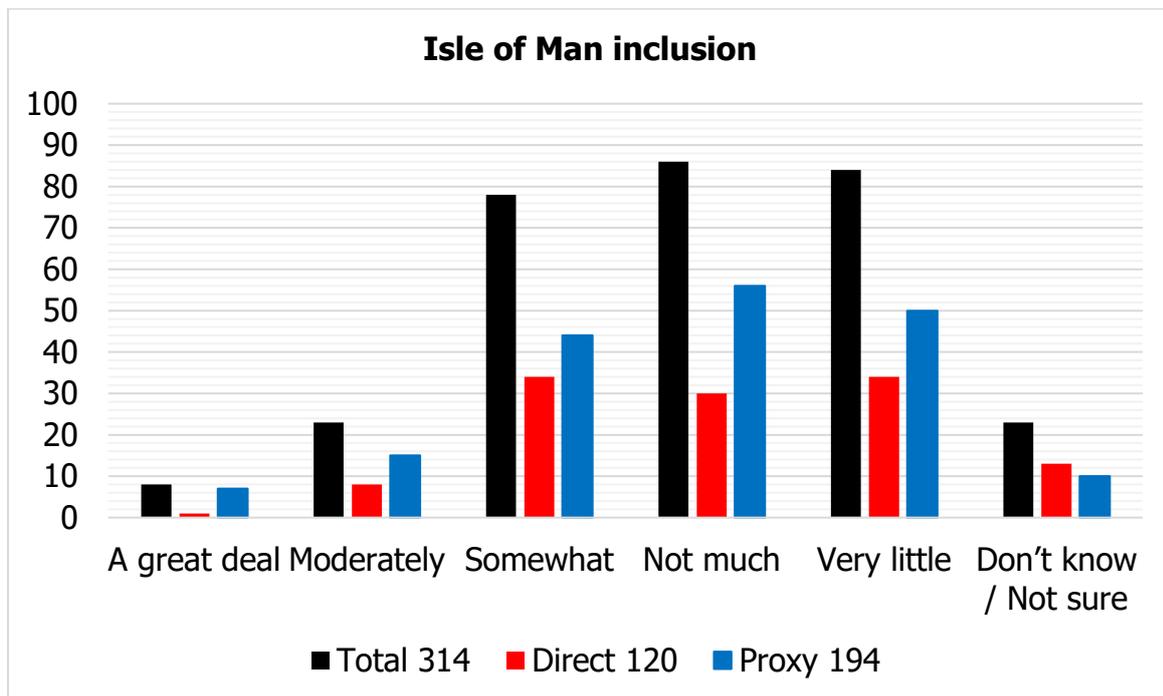
Figure 14. Pie chart of sub-themes for public awareness



2.3.1. Acceptance and inclusion

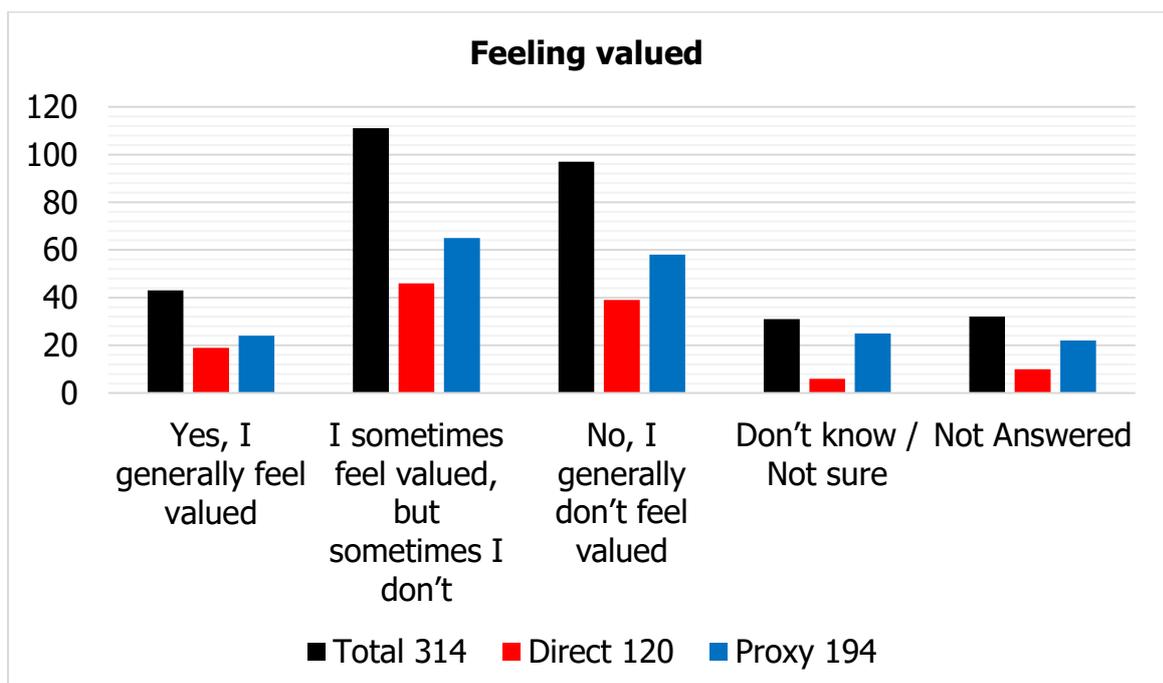
Figure 15 shows how much people feel the general population of the Isle of Man accepts and includes autistic people. The majority of people, 54%, said there was not much or very little general acceptance and inclusion. Although 25% said that the Island's population are somewhat accepting, only 10% said the Island is very or moderately accepting and inclusive.

Figure 15. Bar chart of acceptance and inclusion in the Isle of Man



We also asked people whether they generally feel valued by other people. Figure 16 shows the majority of people said they sometimes feel valued but sometimes don't. Many people said they generally don't feel valued, and relatively few people told us they generally do feel valued.

Figure 16. Bar chart of feeling valued



We asked people in which areas of life they feel most and least accepted and included. Figure 17 shows that most people feel more accepted and included in their home environments or when they are with someone who can support them. Figure 18 shows that most people feel least accepted in public spaces, in educational settings, and in social groups.

Figure 17. Bar chart of where people feel most accepted

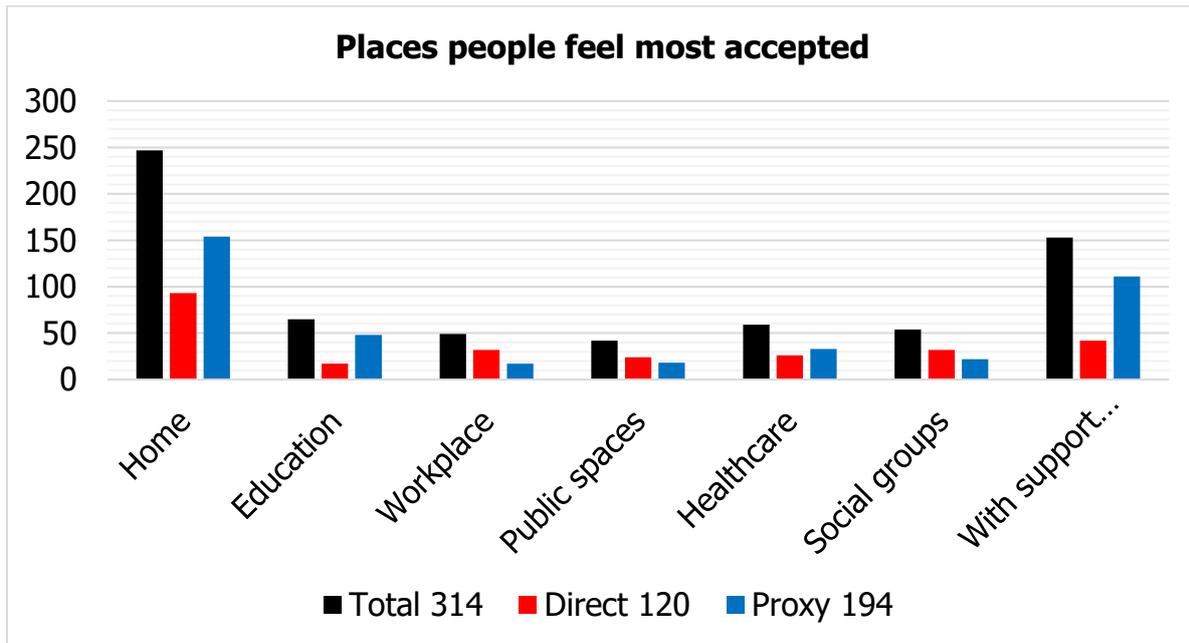
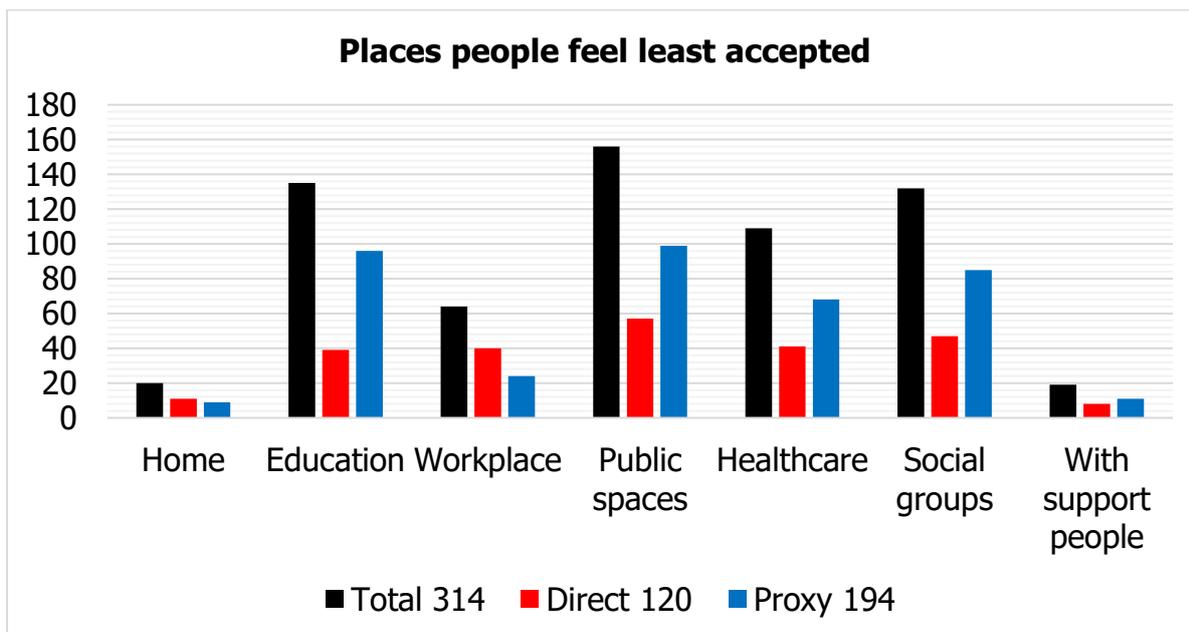


Figure 18. Bar chart of places people feel least accepted



Many people described the effects of being judged or misunderstood, telling us they feel:

"I feel like a burden everywhere because people don't understand me and I'm often trying way too hard to please people and not be a burden...I feel like people wish I was better".

"I have no value in society at all".

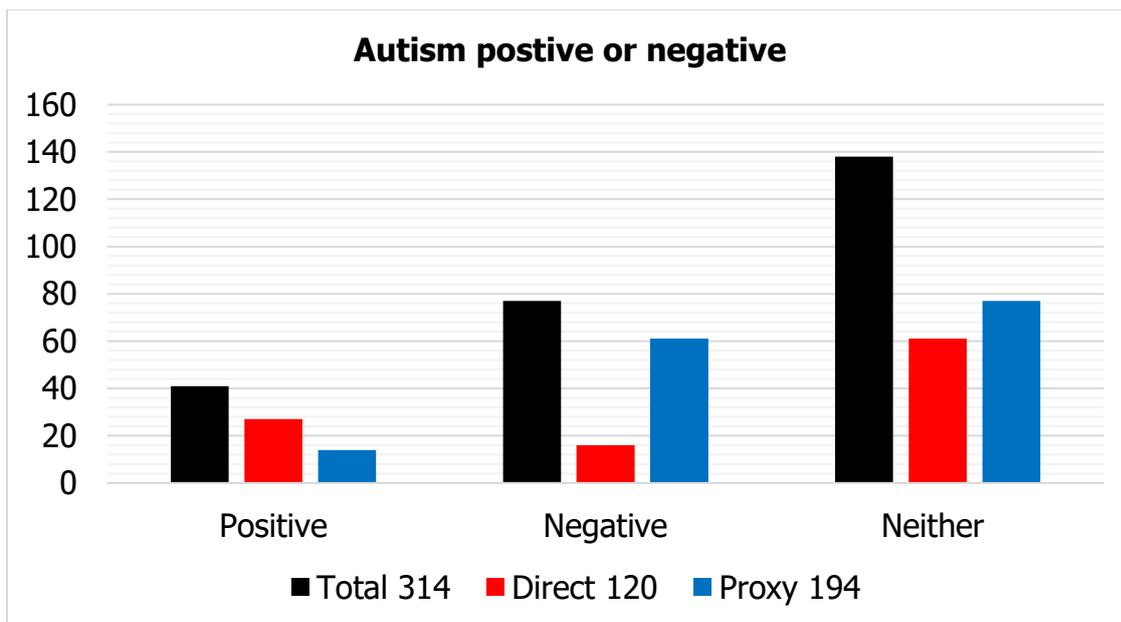
"In public where I don't feel safe I find it so challenging and I'm ashamed of being autistic and not fitting in and being able to do normal things without getting overwhelmed".

"I think our son is seen as a nuisance in the main".

"Seen as weirdos or outcasts from society".

We asked people whether they thought of their autism as a mostly positive or mostly negative thing. Figure 19 shows that most people, 44%, said their autism could be both positive and negative in different ways. Notably, autistic people were more likely than proxy responders to say their autism is a mostly positive thing, and much less likely to say it is a mostly negative thing.

Figure 19. Bar chart of autism positive vs. negative



Some of the things people told us about the positives and negatives of autism:

"Autism is just a difference, not a bad thing. It can be disabling for some people but not for others, and many people who are disabled by their autism would not be if they were properly accommodated by our community".

"I think of my autism as a superpower. Ignorance and prejudice from others as well as society not understanding my autism is what is problematic and causes me pain and issues daily".

"Being autistic is wonderful, I have a very unique look on the world".

"I love that I question everything and continue to learn. I love that I can picture things in my head and then just draw them".

"One of the things that bothers me most when I talk about autism is the widespread assumption that it's a negative thing...I wouldn't always say I'm 'proud' to be autistic, but I also don't hate it. Without my autism I doubt I'd be doing what I do for a living".

"Sometimes – e.g. in highly structured, technical situations – I appear very competent, but in other situations, where I can't use logic, I just can't do things or can only do them very slowly".

"Autism is a disability because the environment is the primary factor that disables. With proper support the person is less disabled".

We asked our autistic respondents what they would like more people to know about them. They told us they wanted people to understand that different doesn't mean less:

"I'm not stupid, I'm just different".

"We've all got different traits, there's no point in bullying anyone. You miss out on things you can do if people aren't nice to each other".

"That honesty is not criticism. That eye contact does not equate to attention. That simplifying information makes for easier communication. That my level of empathy is well developed; so much so that it can be overwhelming. That my facial expressions do not always mean what they presume".

"Autism means something different to every individual. I'm always trying my best in any situation. My frame of reference and understanding may be wildly different to someone else's, but communication, rather than assumption, would greatly assist the situation".

"Asperger's is not a mental illness".

"Autistic adults are adults, with very complex inner lives, and autism is a difference, not a deficit. In a society of mostly autistic people, non-autistic people would be considered disabled".

"We can do lots of things and be treated the same, and that, yes, we do need help with lots of things but we should be listened to".

Autistic people also said they wanted more people to understand the importance of giving them time to process, think or adjust:

"I am slow to process verbal communication and need time before I am asked to make a decision. If I am not given time or a chance to ask questions I may agree with things and do what I am told without really wanting to".

"It takes time for me to answer questions – I often find I get talked over – even in Government service situations. It takes time for me to prepare to go somewhere. I will ask questions that may not be apparent to non-autistic people, but to me, these questions are vital".

"I need time to process things, I'm blunt because I speak without thinking. I get extremely overwhelmed around new people and need time to observe before participating".

"Some tasks I may take longer on than others, some I might be quicker".

"Give me a minute to process. Give me instructions in points or short clear sentences. I take time to relax and get into social banter".

Many autistic people also said they would like others to understand more about their sensitivities or sensory issues:

"I can come across off or overly sensitive for no reason in other people's eyes".

"I'm sensitive and I sometimes say things the wrong way, that I don't mean in the way people think I do, and then I panic I've upset them and I dwell on it for days. I get overwhelmed and easily stressed, I feel very sensitive to fluorescent lighting".

"I'm not weird. I just struggle with certain things. I know it looks to you like I'm having a tantrum, but I'm not, I'm so overwhelmed by all the sensory input going on that my body has to shut down to protect itself".

"My sensory differences are real, not just me being dramatic. I'd also like people to understand that when I question them, I'm trying to clarify information – I'm not trying to undermine them".

"I'm not a snob or stand-offish, but I sometimes rather be on my own".

"Masking is incredibly taxing and leads to autistic burnout and harm, but we are taught to mask as much as possible, and only given support if we cannot mask".

2.3.2. Autism and gender

Misunderstandings about autism and gender was a distinct theme in comments about public acceptance:

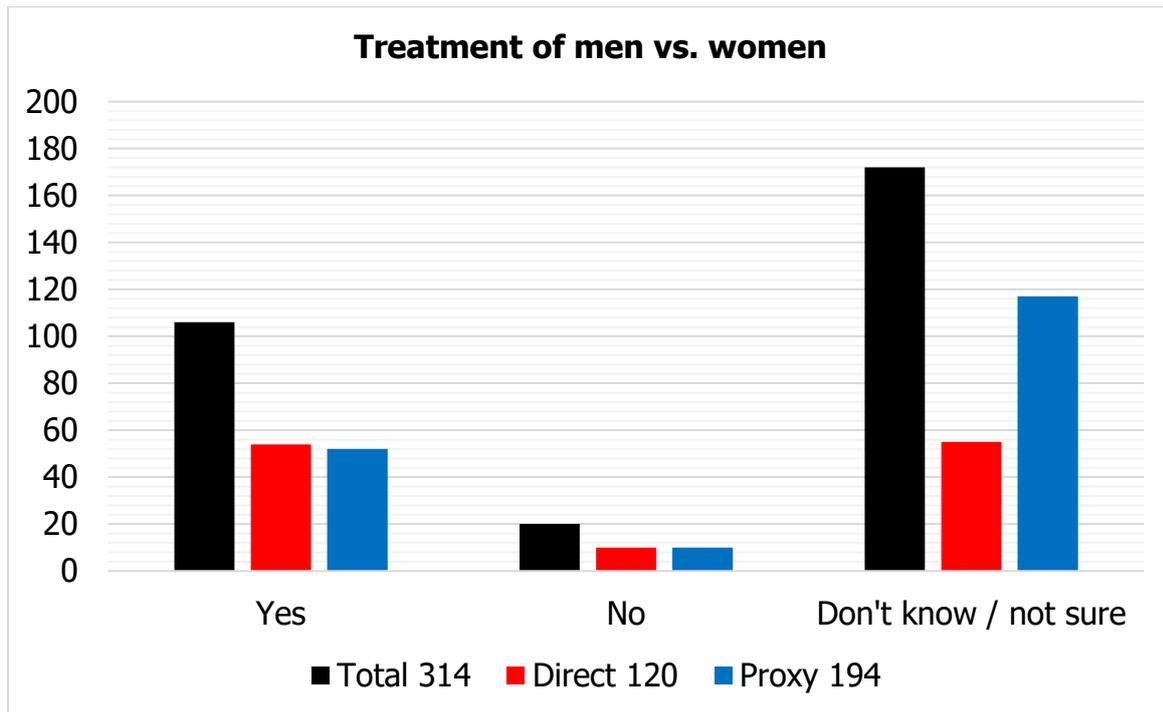
"Being a woman with Asperger's, if I do inform people they either don't believe me or say I'm too sensitive".

"Men are allowed to be blunt and antisocial, women have to be accommodating, always".

"I have a friend who is autistic and she has always had to fight off opinions of being a 'shouty woman', when all she's doing is being honest and forthright".

We asked people whether they thought there was a general tendency to treat autistic women differently to autistic men. Figure 20 shows that most people, 55%, weren't sure, 34% said yes, and 6% said no.

Figure 20. Bar chart of whether people treat autistic men and women differently



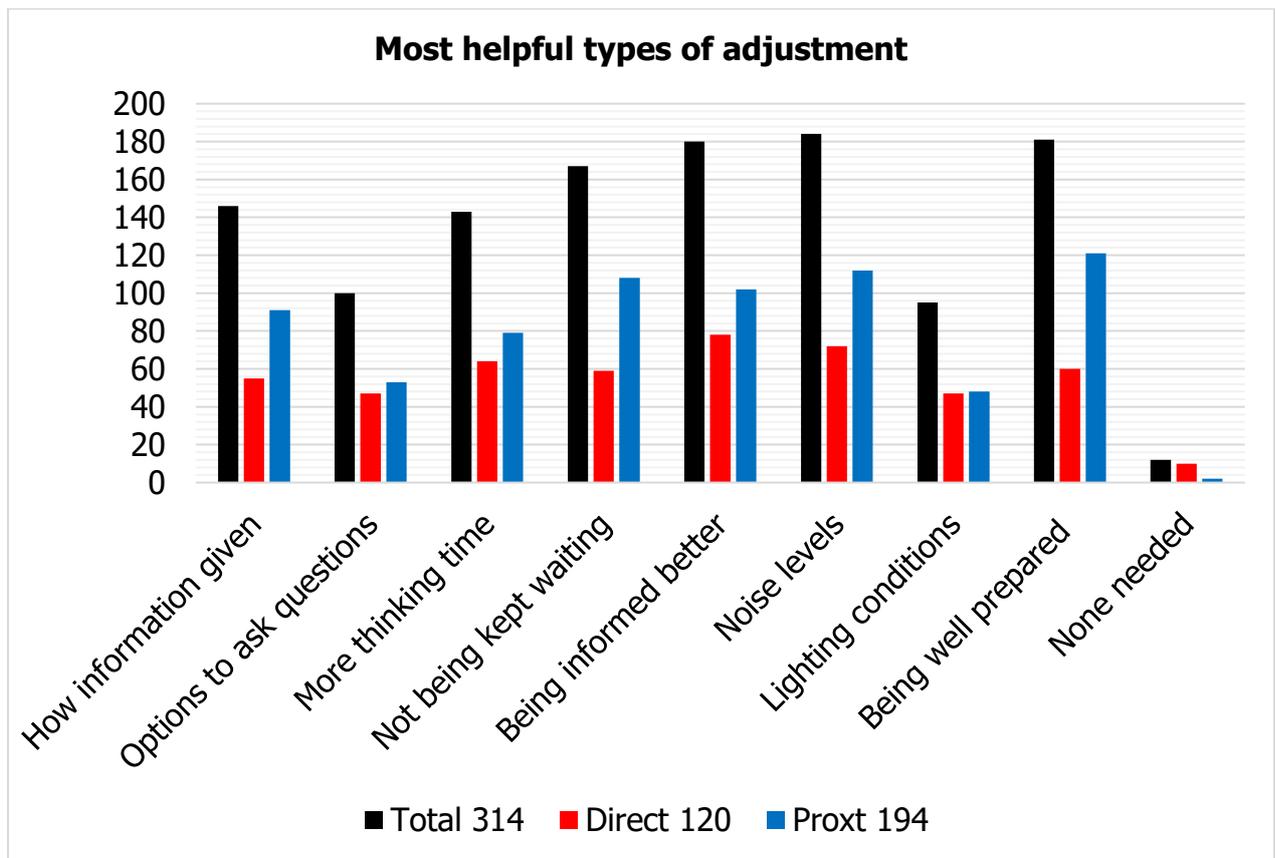
2.3.3. Reasonable adjustments

We asked what kinds of adjustments can help to include people and make them feel more accepted. Figure 21 shows the adjustments rated as most helpful were reducing noise levels, giving clear information, and giving people plenty of time to prepare for things. Also important are not keeping people waiting, providing information in different ways, and giving people time to think, process and adjust.

Some of the examples people gave included:

- Slow lanes and designated quiet hours in shops,
- Designated safe spaces in crowded areas,
- Being helped to avoid queues or crowds,
- Being given detailed and precise instructions and accurate information,
- Being offered different ways to communicate, e.g. phone, email, in person,
- People recognising the sunflower lanyard for hidden disabilities.

Figure 21. Bar chart of most helpful adjustments



We asked people if any places have ever made these kind of helpful adjustment for them. Figure 22 shows that people have experienced helpful adjustments being made across a range of public areas. Of people who said they have had adjustments made, the majority said these were in education settings, although nearly as many said adjustments had been made for them in healthcare settings. Some people, though significantly fewer, have had adjustments made for them in hospitality, transport, and retail settings.

Figure 22. Bar chart of places where adjustments have been made

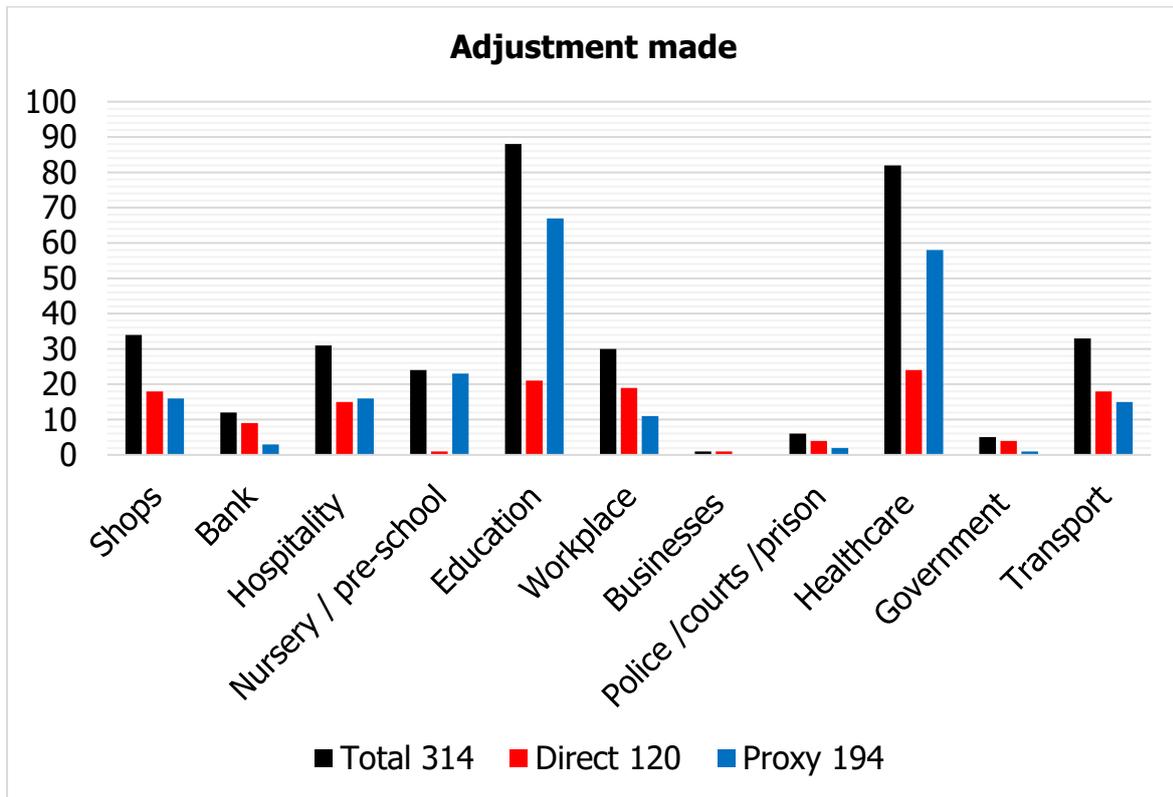
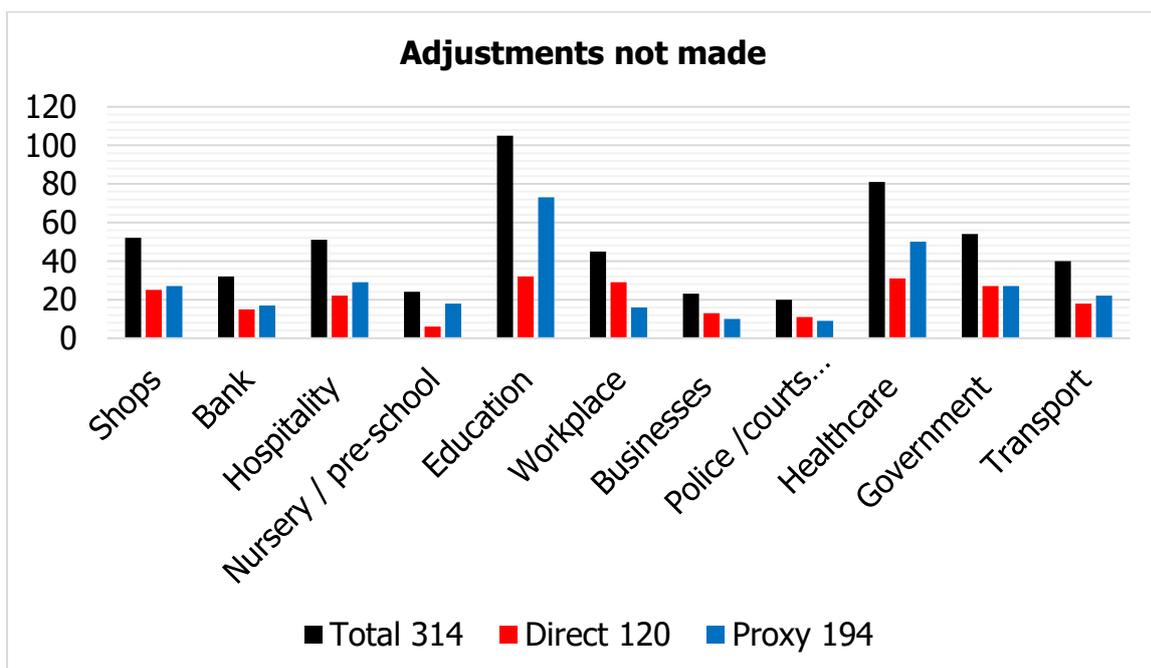


Figure 23 shows that more people told us about failures to accommodate or include them. Across most settings, more (or as many) people told us about failures to make adjustments than about success stories of adjustments being made.

Figure 23. Bar chart of places where adjustments have not been made



Some people told us about not feeling confident or able to ask for help or accommodations to make them feel more accepted and included. Fear of rejection or judgement can stop people asking for things that would help them feel more comfortable.

"I've never had the bravery to ask for any adjustments in most places".

"I am often too scared to ask for help".

"I spend a HUGE amount of energy on masking and trying not to 'act autistic' because of how I'm treated if I don't".

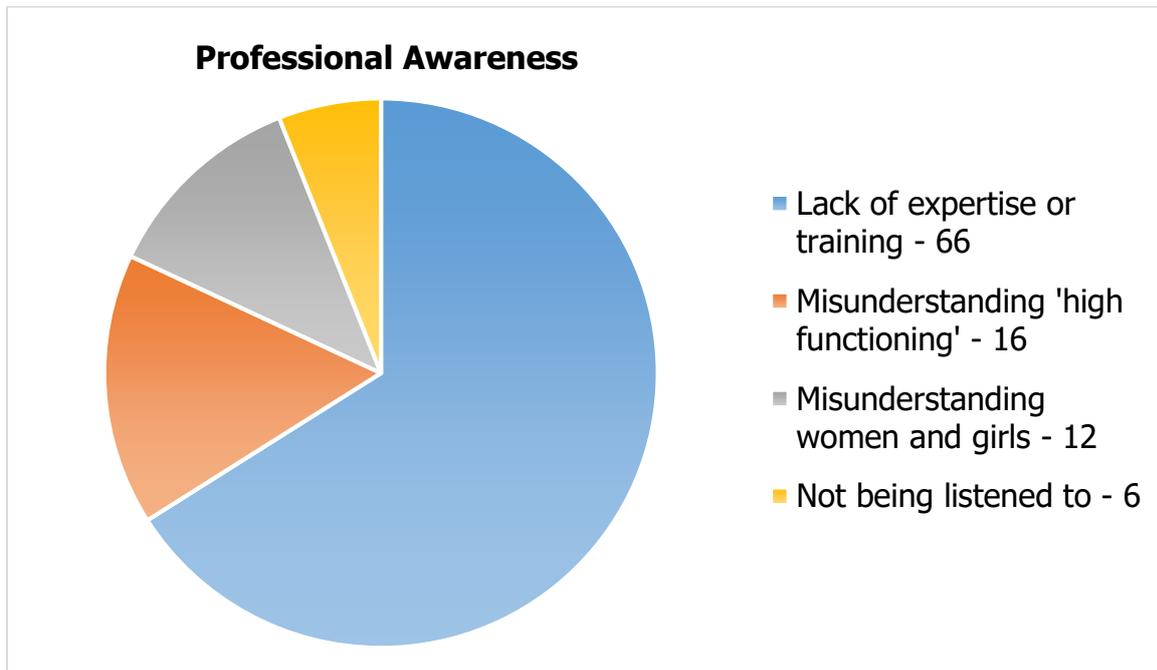
"Part of the problem is that some...organisations and companies won't even consider providing any accommodations without a compelling reason to do so. An autistic person doesn't owe anyone their diagnosis. We shouldn't have to disclose medical information just to be accommodated. If we can get to a place of understanding (rather than just awareness) we could have organisations offering accommodations to everyone automatically because it's the right thing to do and all humans are different".

2.4. Professional awareness

Another commonly mentioned issue was a lack of awareness amongst professionals, with 130 separate comments across the consultation.

Figure 24 shows the most prominent sub-theme within professional awareness was a lack of expertise and training, followed by misunderstanding of 'high functioning' autism, and misunderstanding the presentation of autism in women and girls.

Figure 24. Pie chart of subthemes for professional awareness



People told us they have had negative experiences when professionals have lacked understanding or expertise. These experiences have happened across a range of settings, from health and social care, to education, criminal justice and business.

"In hospital...questions were asked with no context so my mum had to ask them differently or I gave misleading answers, e.g. psychiatrist 'Do you hear voices?', answer 'yes'. Mum 'Do you hear voices when there is no one in the room?', answer 'no'".

"I have been 'accused' of asking too many questions before".

"I really struggle at GP appointments, I often leave upset because I hadn't been able to communicate all that was wrong or troubling me".

"I still have to ask every doctor, nurse or dentist, at every appointment, to explain what is happening and why (before it happens)".

"Teachers and professionals called me naughty and dangerous".

"I get into trouble for things and I don't understand why".

"Police have arrested him because his lack of social skills and difficulties controlling emotion made them think he was on drugs".

People with diagnoses of Asperger's Syndrome or 'high-functioning' autism told us they find it difficult to ask for help from professionals because they are worried about being dismissed.

"I've had doctors roll their eyes and say 'well, you're talking to me just fine and making eye contact, so I don't think you have autism and it's clearly of no concern if you do'".

"They seemed perplexed that I needed help, because I'm high functioning and well qualified".

"My mum was told that I couldn't be autistic as I could look people in the eye".

Autistic women and girls told us they have experienced difficulties caused by professionals not understanding differences in the presentation of autism across different genders.

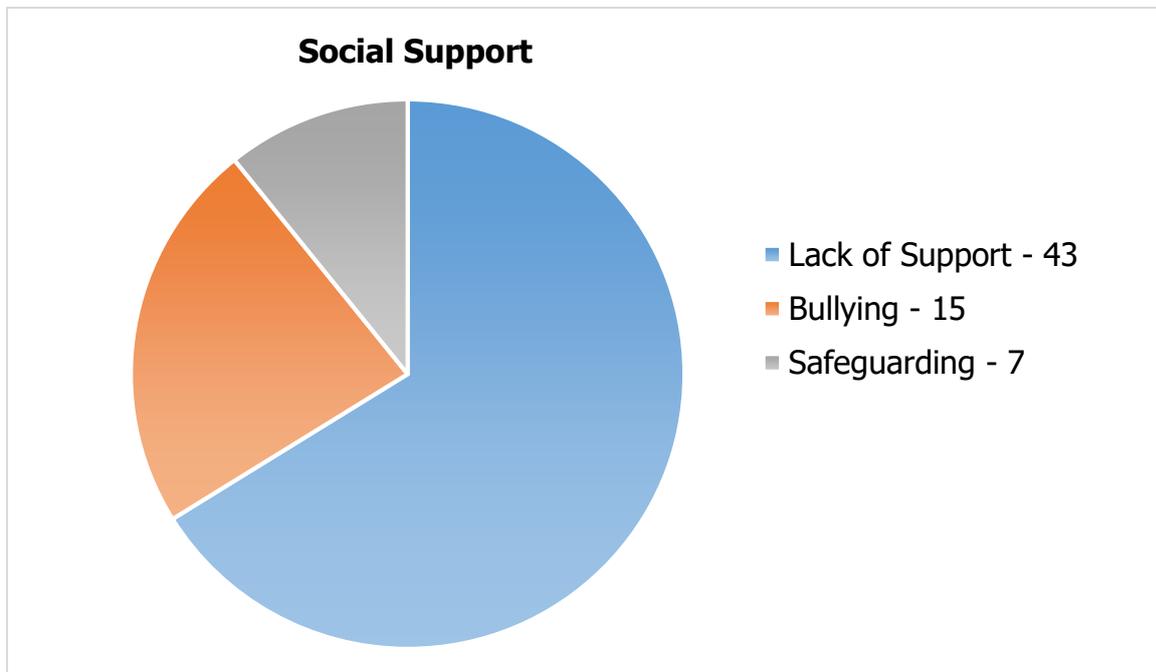
"Medical professionals only 'count' autism in boys who like trains and can't make eye contact".

"We don't present the same way and even mental health professionals dismiss females because they don't present stereotypically male behaviours".

2.5. Social support

There were 65 separate comments relating to social support. Figure 25 shows the three sub-themes for this issue – lack of support, bullying, and safeguarding.

Figure 25. Pie chart of sub-themes for social support



Most comments were from people telling us they need more support with social activities. People told us they want more opportunities to make friends and meet like-minded others.

“I want to meet other people that also have high functioning autism”.

“[It would be good to have] a buddy system to help people if they need someone to chat to or meet up to do something socially”.

“[I would like] more peer support groups and social groups. There are plenty of people who would like to meet up with others and just make friends”.

“Would be nice to meet other women with autism”.

“[We need] an opportunity for Asperger’s teenagers to find like-minded people to form meaningful friendships”

People said they would like to have a greater range of social activities to pick from, and would like to see more supportive social opportunities for adults. Some people suggested more events should be specifically targeted to the autistic community:

“More special events targeted specifically with autism friendly sessions or hours, and making these well known to the community”.

“More public events aimed at autistic people, or at least geared towards them”.

People also told us that the consequences of inadequate social support can be damaging, particularly when people face bullying or exploitation. People told us that they, or the people they support, have experienced bullying across a range of settings, including at school, in work, and in public. A number of people mentioned specific safeguarding concerns, such as overcharging in shops or criminal exploitation.

“He won’t stick up for himself – he’ll agree with what other people want”.

“No one accepts me and often take advantage of me. I suffer from permanent anxiety and am only just coping with life. Very little support”.

“[We] worry as she can be easily taken advantage of”.

2.6. Education

Concerns about access to education were another prominent theme in the consultation, with 60 separate comments.

Figure 26 shows the two largest sub-themes in comments relating to education were a lack of adequate support and the need for more access to higher or continuing education. People also told us about reasonable adjustments not being made, schools not having enough resources, and choosing home or private school alternatives.

Some of the things people told us:

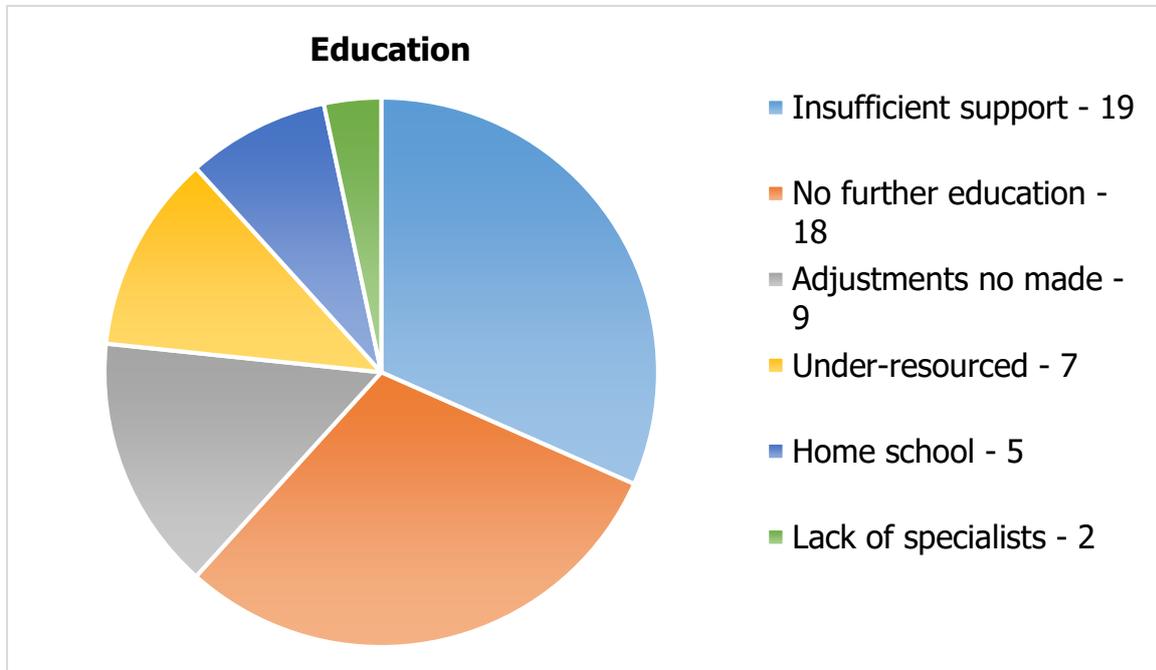
“He’s left feeling that he’s failed due to lack of support helping him participate in school activities”.

“Unless a child is ‘autistic enough’ to be in the special educational needs unit, there is no help whatsoever for them”.

“The team at our school are excellent but first and foremost very busy”.

“Lack of understanding and support led to having to be home educated”.

Figure 26. Pie chart of sub-themes for education



As Figure 27 shows, of the people represented in this consultation between ages 5 and 25, 66% are in full-time education, 7% are in part-time education, and 25% are not in education. Two respondents chose not to answer.

Figure 27. Bar chart of autistic children and young people in education

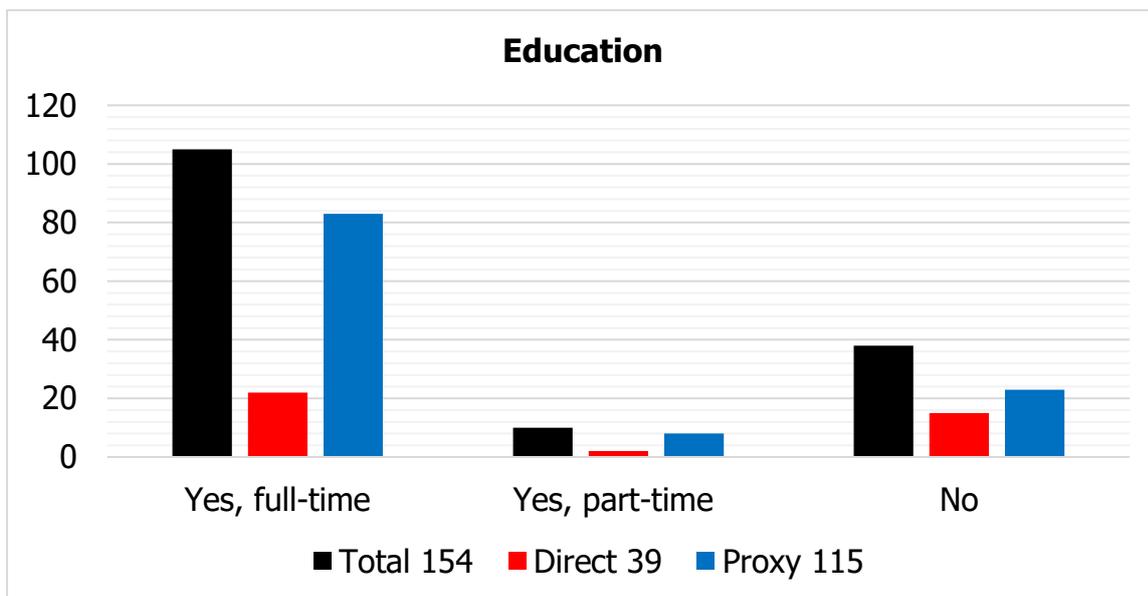
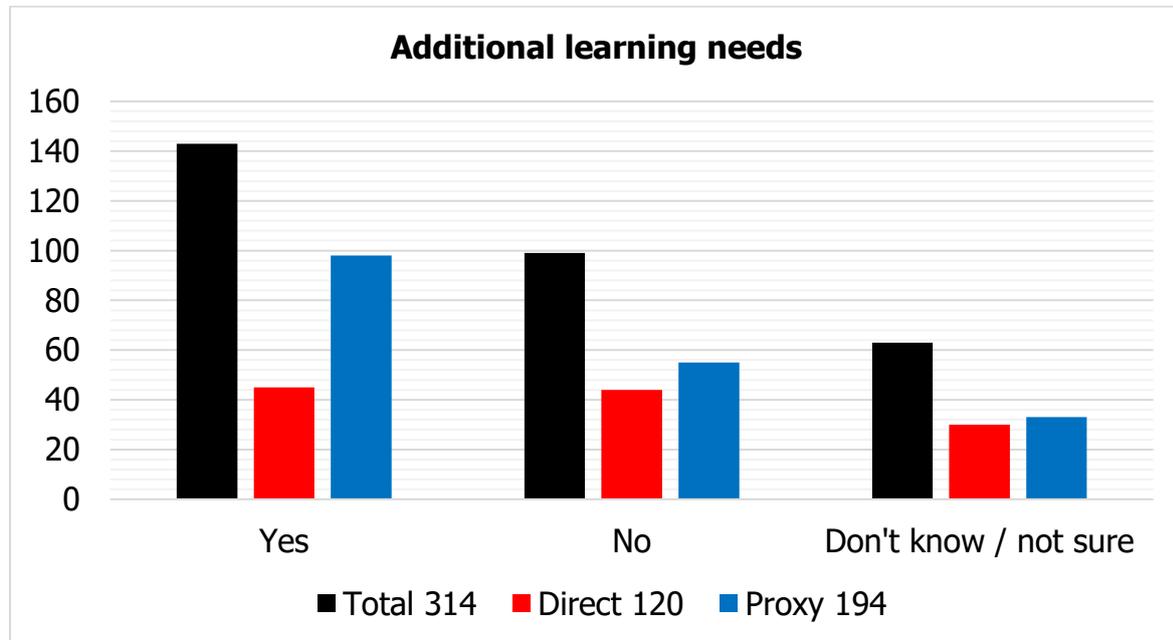


Figure 28 shows 46% of people said they had additional learning needs, such as dyslexia, dyspraxia or ADHD, while 32% said they have no additional learning needs, 20% weren't sure, and 2% chose not to answer.

Figure 28. Bar chart of people which additional learning needs

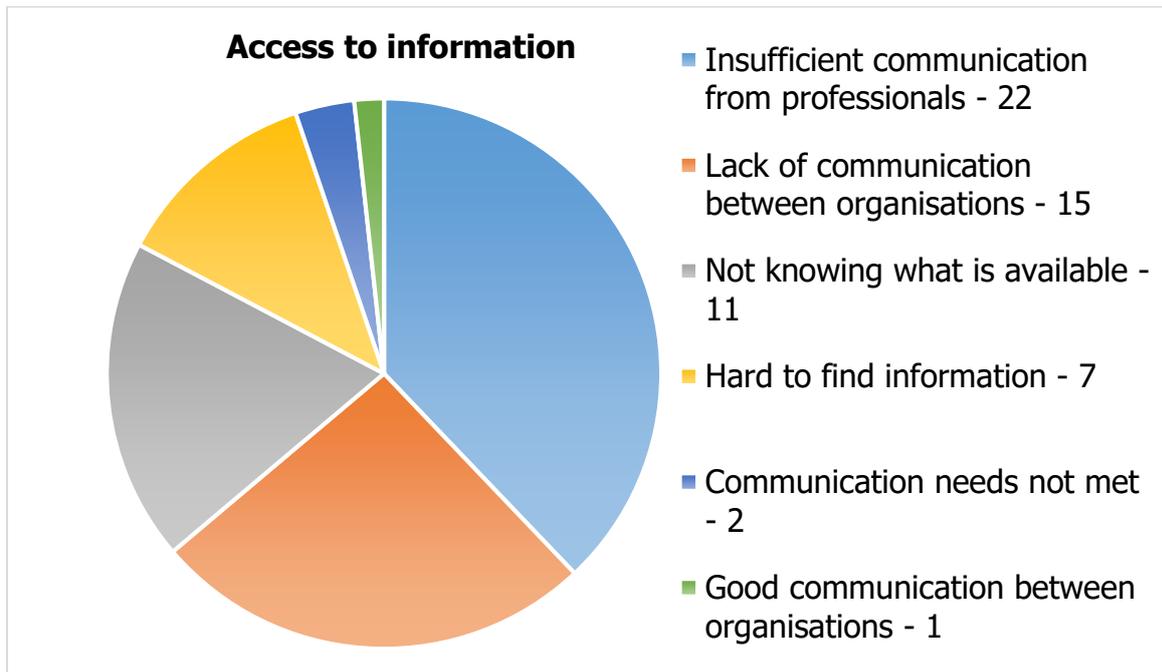


People were also asked if they have a learning disability – 35% said they did, 47% said they did not, 16% were unsure, and 2% chose not to answer. It is worth noting, however, that we did not give define learning disability as an IQ under 70, so it is not clear if these figures represent people who are or aren't eligible for learning disability support.

2.7. Access to information

There were 58 comments relating to difficulties relating to information or information sharing. Figure 29 shows the biggest issue is not being given enough information by professionals. Lack of communication between different organisations, and not being able to find the right information are also concerns for many people.

Figure 29. Pie chart of sub-themes for information



People told us they would have liked to have been given more information by professionals, across a range of situations, but particularly following diagnosis.

“He has had no professional input on how his mind works and why he feels the way he does”.

“Results received in post and that was it, no follow up or discussion regarding the diagnosis and offer of help going forward”.

“Psychiatrist basically said ‘well I’d say you’re definitely on the spectrum, you have ASD, thanks, bye’”.

“Only advice given was to spend time researching the diagnosis”.

People also told us they have had difficulties getting organisations to coordinate or share information with each other.

“I am tired of repeating myself every time I have to deal with a different Government employee”.

“No communication at all between school, CAMHS or social services”.

"Lack of communication between Mental Health and my GP meant that I spend many years waiting to see a psychiatrist who treated my mental health needs, rather than just medicate me".

People told us that helpful information can be difficult to find, and that they struggle without knowing where or how to get support.

"A pack should be available...explaining what is available from Government and also from charities on the Island".

"I need support, someone in a similar situation to talk to. Someone I can ask about services available for our family".

"We would like more support on how to help him. We read as much information as we can but we do feel very alone".

"The way that I have found people who can help is by other parents telling me about services. They have never readily been given, I have always had to find them and ask".

"No one told my mum that I was eligible for DLA, she had to find out for herself".

"The DLA form is geared towards physical disabilities and extremely hard to complete as a neurodiverse person".

2.8. Employment

There were 44 separate comments relating to employment. Figure 30 shows that of the people represented in this consultation between age 20 and 75, only 32% said they were in paid full-time employment. A further 22% are in part-time employment (including voluntary work), and 6% are actively seeking employment, but 38% are not in any form of work.

Figure 30. Bar chart of adults in employment

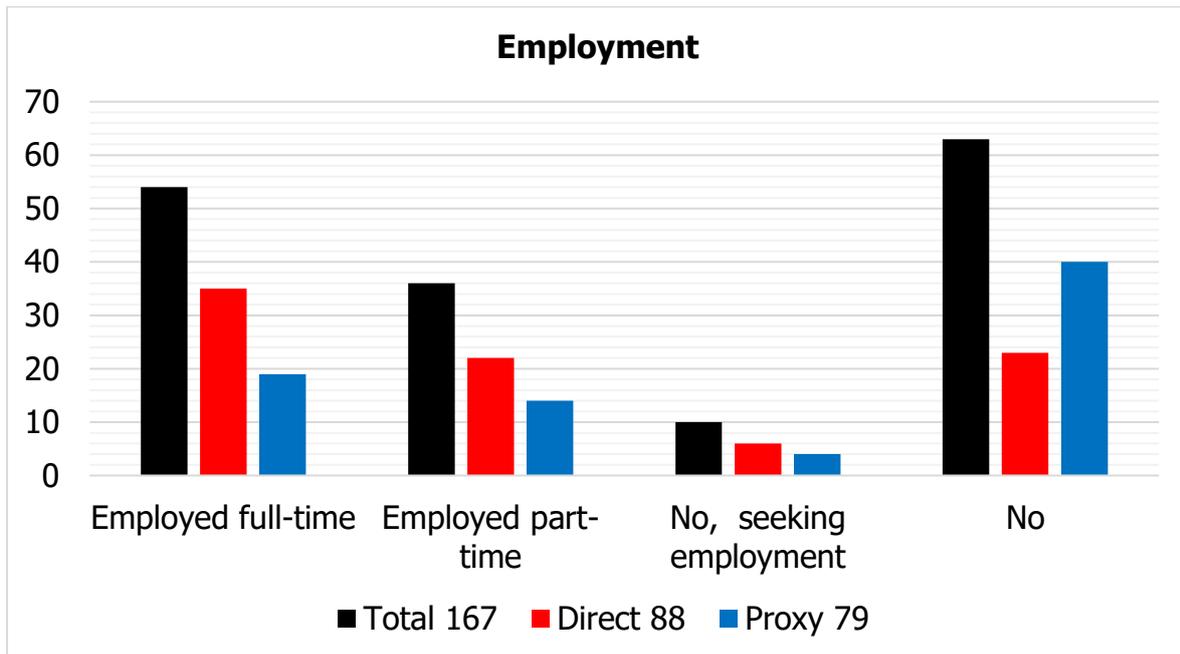
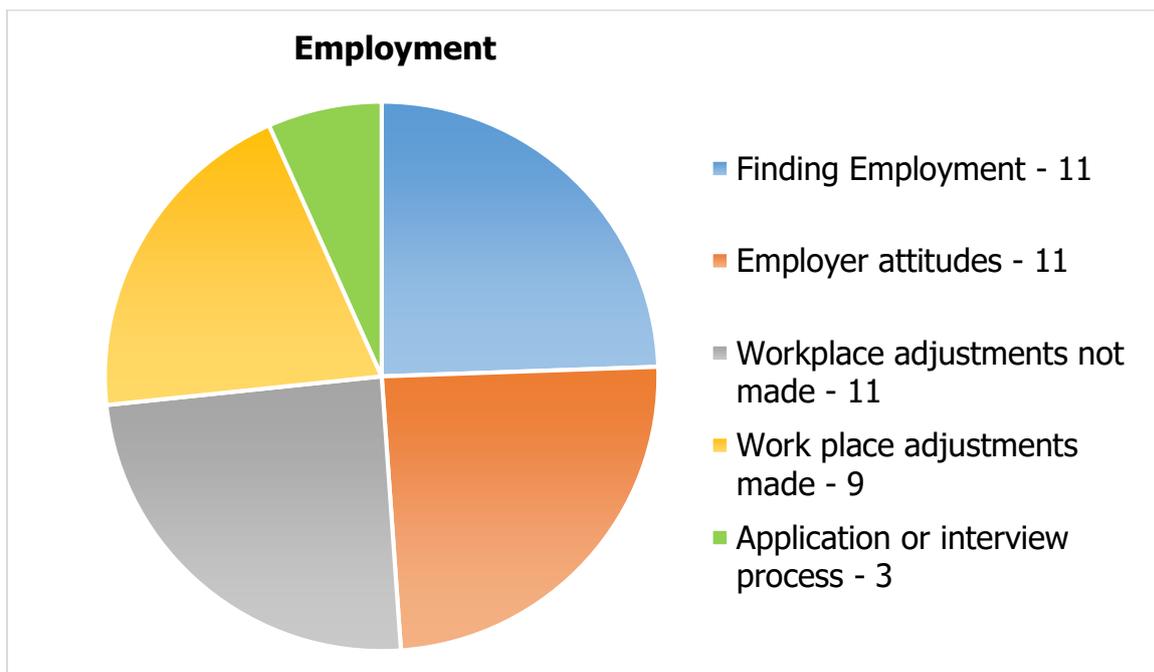


Figure 31 shows the comments were evenly split across three sub-themes; difficulties finding employment, employer attitudes, and inadequate workplace adjustments. Other sub-themes were helpful workplace adjustments and difficulties with application or interview processes.

Figure 31. Pie chart of sub-themes for employment



People told us employment is fundamental to their sense of value and belonging, but they have struggled to find support to enter the workplace.

"Once I left college, I tried to get a job. Went to the job centre in Douglas and explained my diagnosis, was instantly asked if I wanted to go on disability, reiterated that no, I want a job, I just need assistance with the interview process and what to expect".

"[He] is finding it very hard to get a permanent job. Only option from Markwell House was voluntary, he wants to earn his own money".

Some people told us that inaccessible application or interview processes make finding a job difficult.

"Don't want to disclose autism at application/interview phase for real fear of rejection".

People said they would like to find more employers who see their benefits in the workplace and are willing to make reasonable adjustments.

"I do try hard at my jobs and I want to work hard, I just need help doing that sometimes".

"I suffer from extreme anxiety, which means I have struggled to hold down any full time work. My anxiety stems from being slow to process instructions and understand new things. I am worried about looking stupid/people being impatient with me".

"Companies [don't] allow people to work without being sociable or team players. Many jobs do not require social skills for people to provide value".

"Companies mention in every job advert that someone needs to be a good communicator and team player, regardless of whether this is necessary to do the job".

People told us about a mix of negative and positive experiences in the workplace. Some people have found employers who are willing to make helpful adjustments to accommodate autistic employees, but others have had negative experiences when asking for accommodations at work.

Some of the positive experiences people told us about:

“When I’m at work my co-workers don’t mind repeating instructions, even if they have to do it multiple times”.

“I am lucky to work in an industry where neurodiversity is both common and helpful”.

“[Workplace] not applying the appraisal system in the same way”.

Some of the negative experiences people told us about:

“I’ve experienced previous employers who say they understand, but refuse to accommodate, even when given reports from medical professionals”.

“The feedback I’ve received, particularly from a work setting, is that my ‘deficiencies’ massively outweigh any talent or skills I can bring to an organisation. This is utterly demoralising”.

“He had a part time job and was let go because he wasn’t fast enough”.

2.9. Effects on family

There were 34 separate comments about the effects that poor support for autism can have on someone’s family. Many people told us they were reliant on family support, with no other suitable options for accommodation or help with support needs.

“I feel that no one would have helped me if I didn’t have my Mum to organise it”.

“Have assistance from family for day to day living, paper work and organising medical care”.

People told us that families often need more support, and feel like they don’t have enough help or advice to care for their loved ones.

“No family support is provided for families like ours”.

“His first school could not accommodate his needs which proved very stressful and traumatizing for the whole family”.

“It has affected my mum’s mental health trying to support me”.

“Families are getting to the point of being supported on child protection plans because respite provision and support for autism has not been effectively provided”.

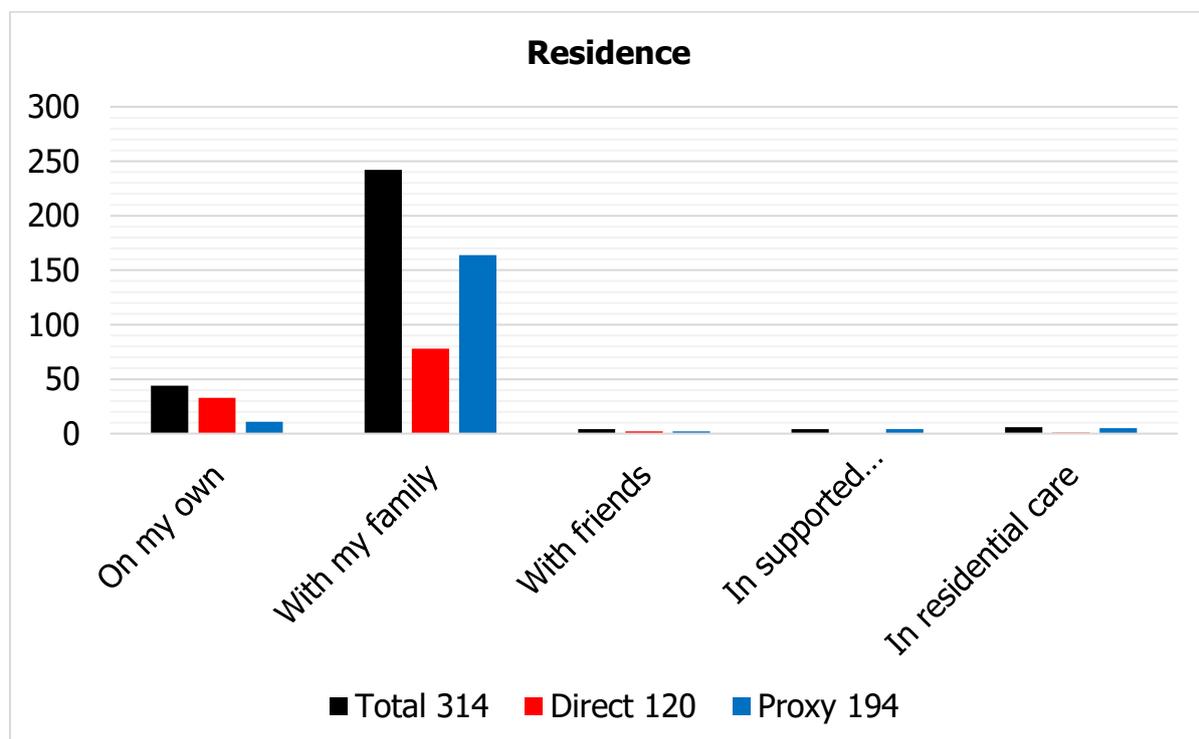
People also told us that families can struggle with the economic effects of not having enough support. Some people struggle to balance caring with work, and others have had to leave the workplace entirely.

“Husband has given up his pension and career 16 years early to be full time carer with lack of facilities over here”.

“I had to give up my job because there is no help for families with children with additional needs”.

Figure 32 shows 77% of people said they live at home with family, and 14% said they live alone. There were 4 people who live with friends, 4 in supported accommodation, and 6 in residential care.

Figure 32. Bar chart for residence



2.10. Medication

There were 28 separate comments about psychiatric medication. Some people told us they had felt pressured to take medication in order to access further forms of support:

"I did ask to be tested, but was told only if I went on medication first for anxiety so I was never seen for diagnosis".

"My daughter is medicated so we still have appointments with CAMHS".

Other people told us they think mental health services place too much emphasis on medication over other types of support.

"Medication is given over support".

"Overly focused on medicating children rather than strategies that could help parents to manage behaviours".

"[They] wanted to put me on sedatives instead of adapting my support in order to help with the challenging behaviour I was displaying".

"It felt like, oh you have autism, sorry we can't help you really other than if you need medication".

"No support, just medication".

"CAMHS only offer medication".

3. Listening to everyone

Part 2 of the consultation was open to everyone who wanted to be involved in the conversation about improving support for autistic people in the Isle of Man. The autistic people and their supporters who completed Part 1 were joined in Part 2 by a range of professionals and other interested parties.

3.1 Barriers and priorities

We asked everyone what they thought were the biggest barriers to accessing support for autistic people in the Island. Figure 33 shows a majority, 64%, said they thought lack of funding was one of the biggest barriers.

The top 3 barriers chosen by autistic respondents were professional expertise, public understanding, and waiting times.

The top 3 barriers for proxy responders were funding, waiting times, and professional expertise.

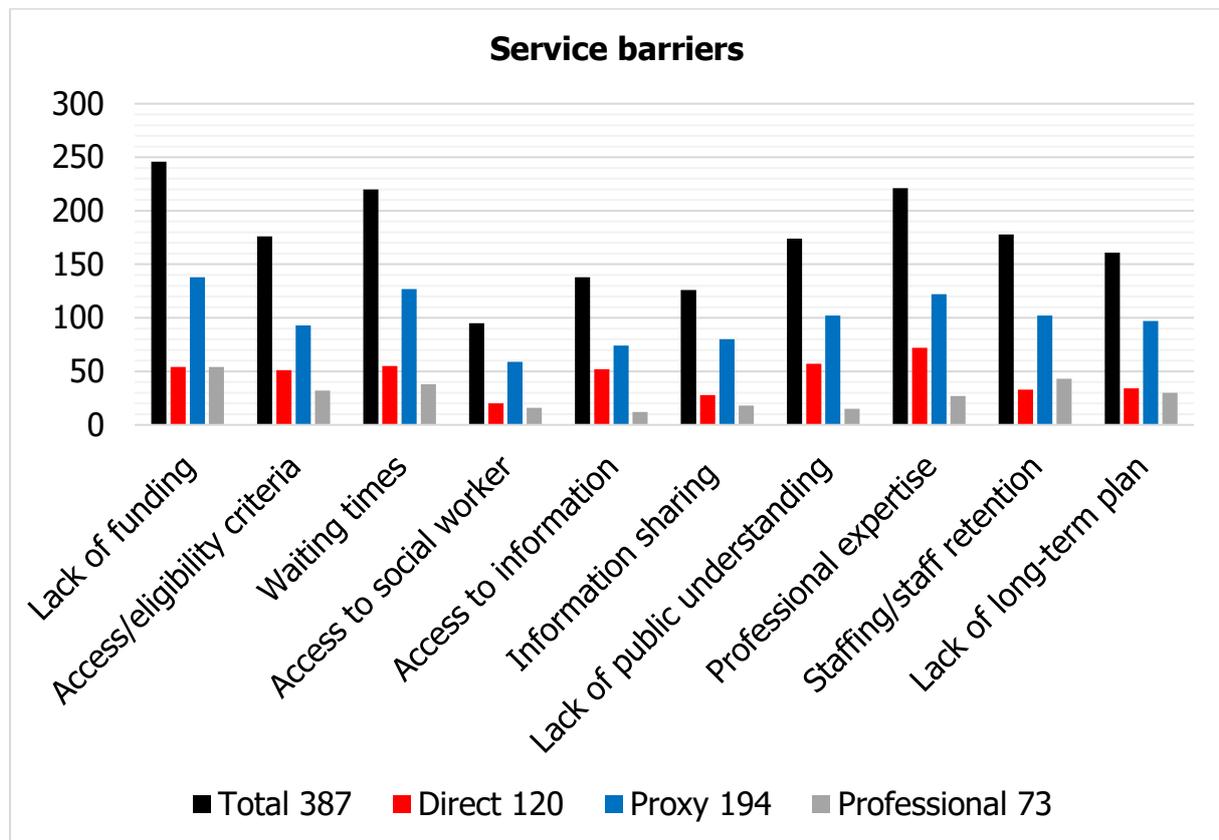
The top 3 barriers for professionals were funding, staffing or staff retention, and waiting times.

A number of professionals also said a lack of training was a significant issue. Some professionals mentioned a specific lack of resources in occupational therapy:

“Perhaps one of the greatest challenges is the lack of access to sensory profiles for adults. No occupational therapy resource exists for this, meaning that the sensory needs of older autistic people go unmet, resources cannot be accessed, and far greater effort has to be expended treating symptoms in terms of behaviour”.

“OTs are not actively providing sensory integration assessments which are essential to understand and support the sensory needs of autistic people”.

Figure 33. Bar chart of barriers to accessing support

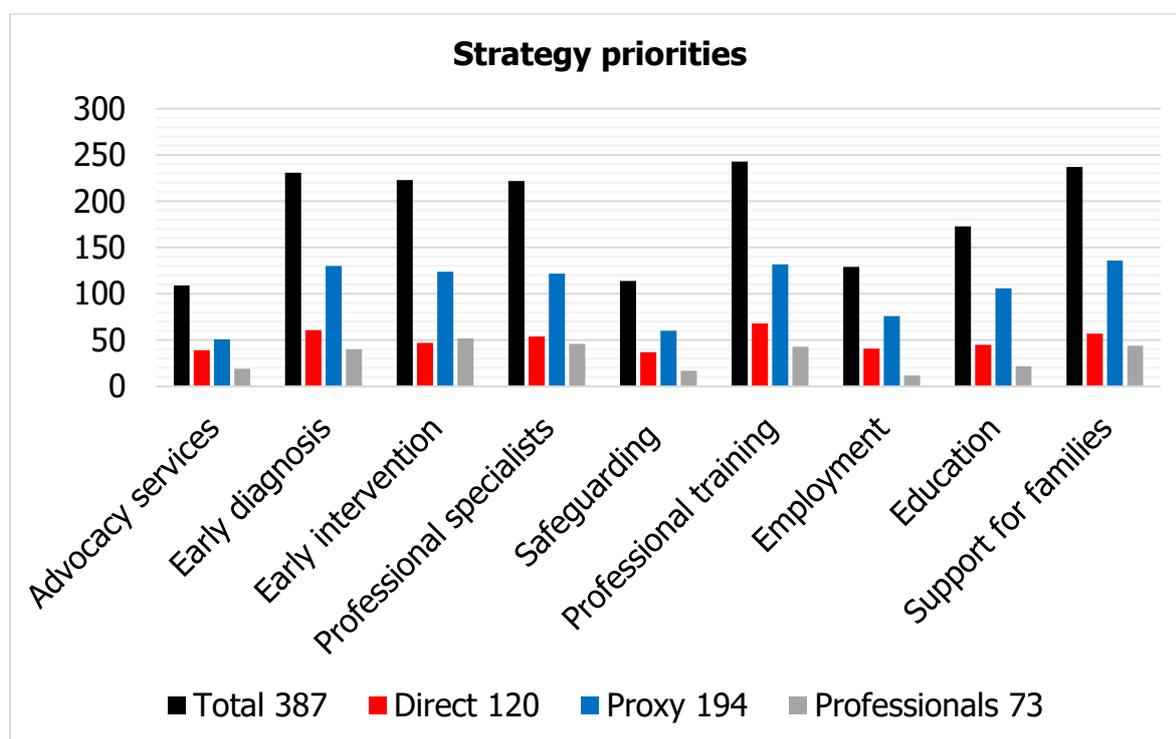


We asked everyone what they would like to see prioritised in the National Autism Strategy. Figure 34 shows that training and education for professionals was the most common answer, with 63% of people choosing it as a top priority.

The top 3 priorities for both autistic and proxy respondents were training for professionals, early diagnosis, and support for families.

The top 3 priorities for professionals were early intervention, professional specialists, and support for families.

Figure 34. Bar chart for strategy priorities



3.2. Examples of good practice

We asked people to tell us where they had seen good practice in supporting autistic people in the Isle of Man.

People told us about a broad range of positive experiences across the Island, in public services, private businesses, charities, shops, hospitality, sports and clubs. There were 90 separate organisations specifically mentioned as examples of good practice.

The 10 places with the most positive mentions were: the Pre-School Assessment Centre (PSAC); the Autism and Social Communication Liaison Officer (ASCLO); Crossroads Isle of Man; Autism Initiatives; the Community Dental Service; Autism in Mann; the Co-op; the Children’s Centre Community Farm; and Villa Gaiety.

People told us what good practice means to them, and gave examples of the things that can make an experience positive. Common themes included people showing patience, communicating clearly, and being flexible and willing to adapt.

“They took time to listen”.

"Individuals in healthcare who have been very kind and patient...Explaining that they are going to do and checking I am OK at each step".

"[They] asked me what would make it easier, what I could cope with, etc."

"Understanding that it can take more time to resolve an issue and to keep trying and not just give up because this individual is not cooperating".

Although many people told us about specific positive experiences, more than 30 people told us they have not seen any good practice in supporting autistic people on the Isle of Man. Of the organisations which were given positive mentions, nearly 20% were also given some negative mentions. Although there are clearly pockets of excellent practice, people told us it isn't consistent or reliable, and there is room for improvement in all sectors.

3.3. Making and autism friendly Island

We asked everybody what would make the Isle of Man more autism friendly. People gave us lots of different answers, with a mix of broad ideas:

"Celebrate autism".

And specific suggestions:

"A DLA form that is specifically for autistic people".

By far the most prominent theme in people's answers was education to raise awareness, understanding and acceptance across all sections of society.

"More awareness and acceptance. Telling all Government staff to be aware of the signs someone may be autistic, but also making sure all members of the public are given time and the opportunity to ask questions before making decisions about the healthcare or education or whatever it may be".

"More awareness that neurological differences are a normal part of society and these differences actually play an essential part".

"Education and acceptance".

"More understanding of the way Asperger's people think and behave and understanding that this could be an asset not a disability".

"More public awareness and acceptance of autism. It should be taught in schools from a young age. If kids grew up to know more about autism and ADHD (and neurodivergence in general), then we'll all end up a much more tolerant society".

"Awareness, and to remove the weirdo and male stigma associated with it. It needs to be aware how common it actually is".

"For the needs of autistic people to be automatically thought of in the same way as people who are blind or deaf".

People told us an autism friendly Island requires true inclusion and ensuring the autistic community have a voice.

"Greater emphasis on the voices and opinions of autistic people, rather than those who support or purport to advocate for us. Nothing about us, without us".

"We MUST elevate the voices of actually autistic people, especially adults".

"Stop trying to fix autistic people, we're not broken, we don't need fixing, we need to be understood".

People also told us making the Island friendlier would require greater investment of public resources to support the autistic community.

"Major changes in educational, mental health and financial support structures".

"More support services for adults".

"We need some out of school clubs like scouts, guides, sports, walking, crafts, etc. that are subsidized".

"More services for the different people on the spectrum".

A number of people said they would like to see wider recognition of the sunflower lanyard scheme for hidden disabilities.

"More recognition of the sunflower lanyard scheme".

"Asking those of us who wear the sunflower lanyards what they can do to help".

Finally, for many people, a friendly Island means traa dy liooar - giving each other enough time, and showing patience.

"People being more patient".

"Patience and kindness are key".

"Be kinder and more patient".

"More empathy and compassion".

"Understanding, care and patience".

"Be more tolerant".

"Patience. Simplified information. Kindness".

Acknowledgements

We would like to thank all of the organisations and individuals who helped us to design and execute this consultation. In particular, we are grateful to the organisations who helped us reach members of our autistic community by hosting drop-in sessions: Autism Initiatives, Crossroads Isle of Man, University College Isle of Man, and Autism in Mann.