

# **Hampshire Autism Strategy**

## **2022 public survey findings**

# Background

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Between 15 August 2022 and 09 October 2022, the Hampshire Autism Partnership Board (HAPB) ran a public survey to inform the Hampshire Autism Strategy, to be published later in 2023. Hampshire's Autism Strategy will tell services in Hampshire how they should work with and support autistic people.

The Hampshire Autism Strategy will address 6 priorities:

1. Improving understanding and acceptance of autism within society
2. Improving autistic children and young people's (CYP) access to education, and supporting the move from childhood to adulthood
3. Supporting more autistic people into employment
4. Tackling health and care inequalities for autistic people
5. Building the right support in the community and supporting people receiving care
6. Improving support within the criminal and youth justice systems

In total 455 responses were submitted to the survey, of which 417 used the generic form and 38 used the Easy Read form.

**Hampshire Autism Partnership Board would like to thank everyone who took the time to share their views, experiences, and ideas.**

## Headline findings

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When asked to identify ways that services in Hampshire could support autistic people, suggestions most commonly related to support for children and young people, including support for their education, and support to improve their health outcomes later in life, as well as ensuring that there was support for their parents and carers.

Activities which autistic respondents felt were most difficult and were also most impacted by autism tended to relate to interacting with other people (such as making friends and socialising), taking part in education, attending job interviews, and starting new jobs.

**In** contrast, activities relating to using services, and living independently, were seen as less difficult than average for autistic people with any difficulty less likely than average to be caused by autism.

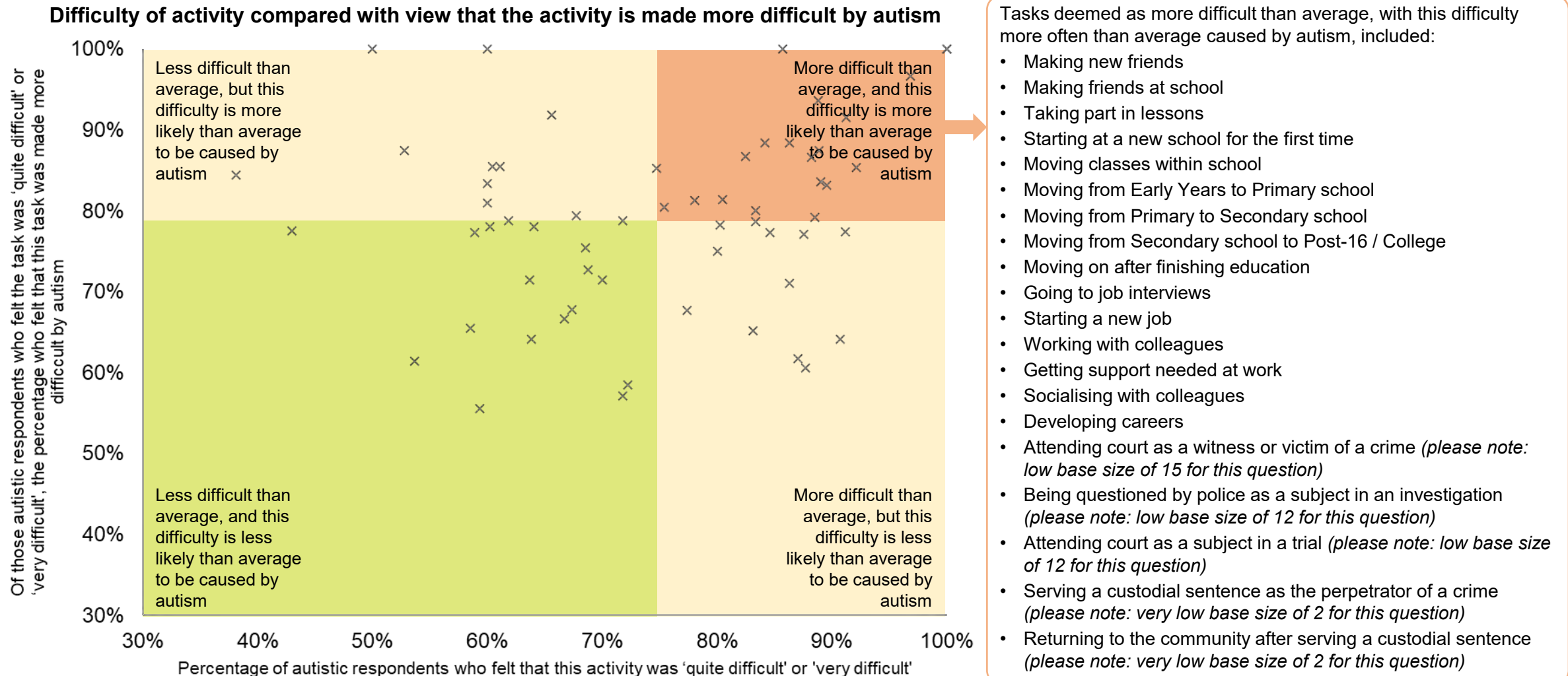
This suggests that autistic people who responded were more confident navigating services and processes than they were at interacting with people in social situations or undertaking new activities.

Respondents regularly mentioned concerns that those supporting autistic people lacked awareness of autism and the behaviours and needs of autistic people, particularly in relation to employment, education, healthcare services, and the criminal justice system.

Despite these concerns about the awareness of autism amongst service providers, respondents generally felt that the public's understanding of autism had improved over the previous five years, largely due to an improved awareness of autistic people, more progressive social attitudes around autism, and better representation of autistic people in the media.

**Overall views on how to improve the lives of autistic people**

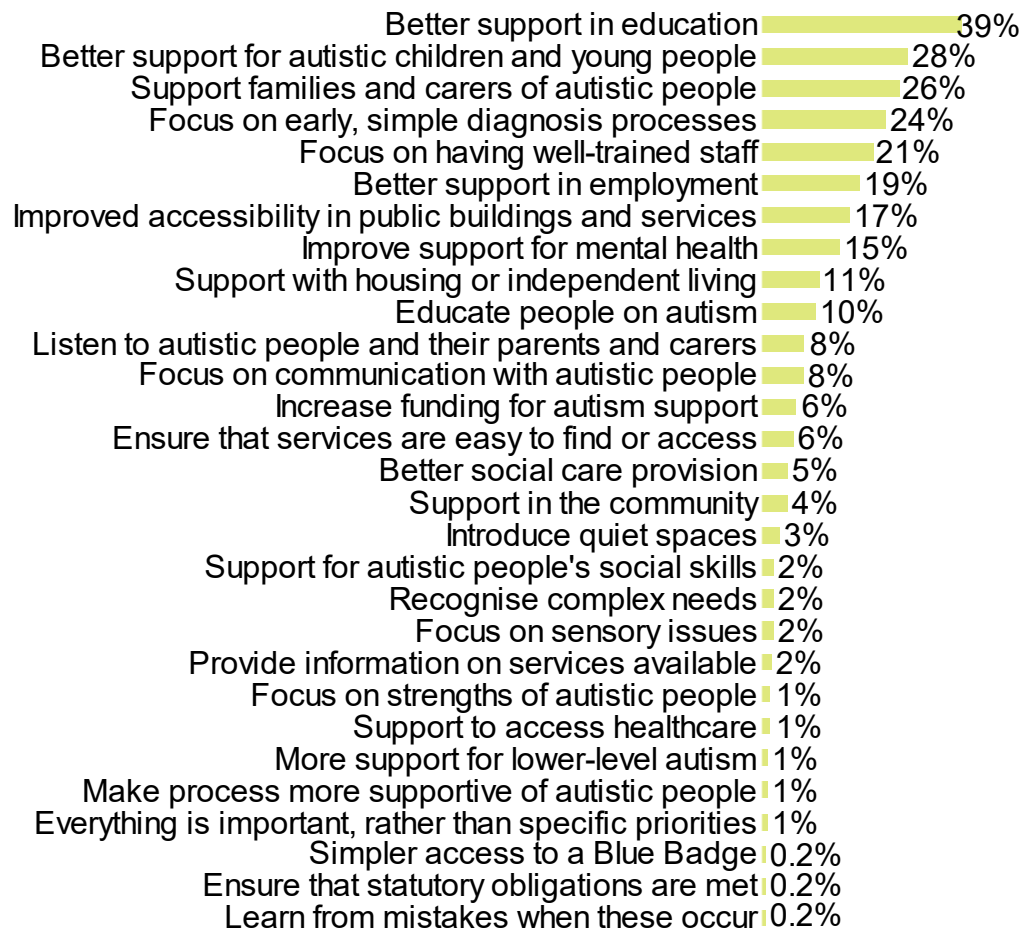
## Overarching views – There are tasks which autistic people find particularly difficult, with autism seen as a main cause for this difficulty



## Overarching views – When asked about how services could generally support autistic people, comments indicated a view that support for children, young people, and their families, should be a main focus

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Thinking broadly, what should services in Hampshire do to improve the lives of autistic people? (Multi-code, base: 411, analysed using an automated text coding process)



Comments most frequently focused on **support in education**, such as access to specialist support or education settings, better training for those working in schools, access to school transport, and more bespoke expectations of autistic children in education.

Improvements for **support for children and young people** (CYP) referred to prioritising resources and support on younger age groups, to give them educational, social, and health opportunities that may not be available to them if not supported at a young age.

Where **families and carers of autistic people** were mentioned, this referred to respite opportunities, assistance dealing with bureaucracy, and groups or sessions that could support those with autistic people in their care, particularly shortly after an autism diagnosis when it can be unclear what support is available.

It was suggested that the **autism diagnosis process** could be improved to make it faster, simpler to engage with, and available earlier to families with undiagnosed autistic children.

**Training**-related comments mentioned the need for public-facing roles to better understand autism, most commonly where they would be working directly with autistic people (such as teachers, doctors, and nurses). It was also noted that those who may encounter autistic people as part of their duties, such as police officers, public transport providers, and those working in public buildings, would benefit from a better understanding of autism and people with hidden disabilities.

Comments about **employment** support mentioned help for autistic people finding work, getting reasonable adjustments in the workplace, and developing careers.

## Overarching views – examples of comments

### Better support in education

*“Make mainstream educators better equipped to help autistic children”*

*“[Autistic students] cannot meet expectations in the same way as other students, and are then being punished for it”*

*“Often school transport is cancelled last minute or no provisions in place at all”*

*“...all teachers should have some form of autism training. Even just a little so they can understand what being autistic is”*

### Better support for autistic CYP

*“Improved early help for children with suspected autism. Including mandatory early years screening and schemes to help parents/guardians/carers identify autistic traits in children”*

*“Increase funding to health and education to improve access to diagnosis, mental health support, social support and reasonable adjustments for autistic young people”*

### Support families and carers of autistic people

*“Provide respite facilities for children with autism. The short breaks scheme is not enough when families need a sufficient break”*

*“More information available on local services sent to parents by email or post”*

*“Access to self referrals and help for parents / cares should be much easier”*

*“Signposting of local support groups and buddying”*

### Focus on early, simple diagnosis processes

*“...encouraging schools to help identify neurodiversity early on, so coping strategies and mechanisms can be found and learned from an early age”*

*“We are seeing more and more children with ASD but the waiting lists for help are 10 months long. Some go to school with nothing in place”*

*“Make it much easier to get a diagnosis and simplify routes to this for both children and adults”*

### Focus on having well-trained staff

*“Introduce mandatory training in public facing roles on how to support autistic people”*

*“Autism is a specialist subject and should be dealt with by trained specialists”*

*“More training for teachers in what to look out for, how to react to a young person who is struggling with overloaded senses”*

*“All people facing roles and employers should have mandatory autism awareness training”*

### Better support in employment

*“Better understanding from the employment agencies running job centres”*

*“Raise awareness of work place adjustments so people with autism can work and progress in their careers”*

*“Specialised advice on gaining employment...such as help job application forms and particularly interviews”*

*“More opportunities for supported volunteering”*

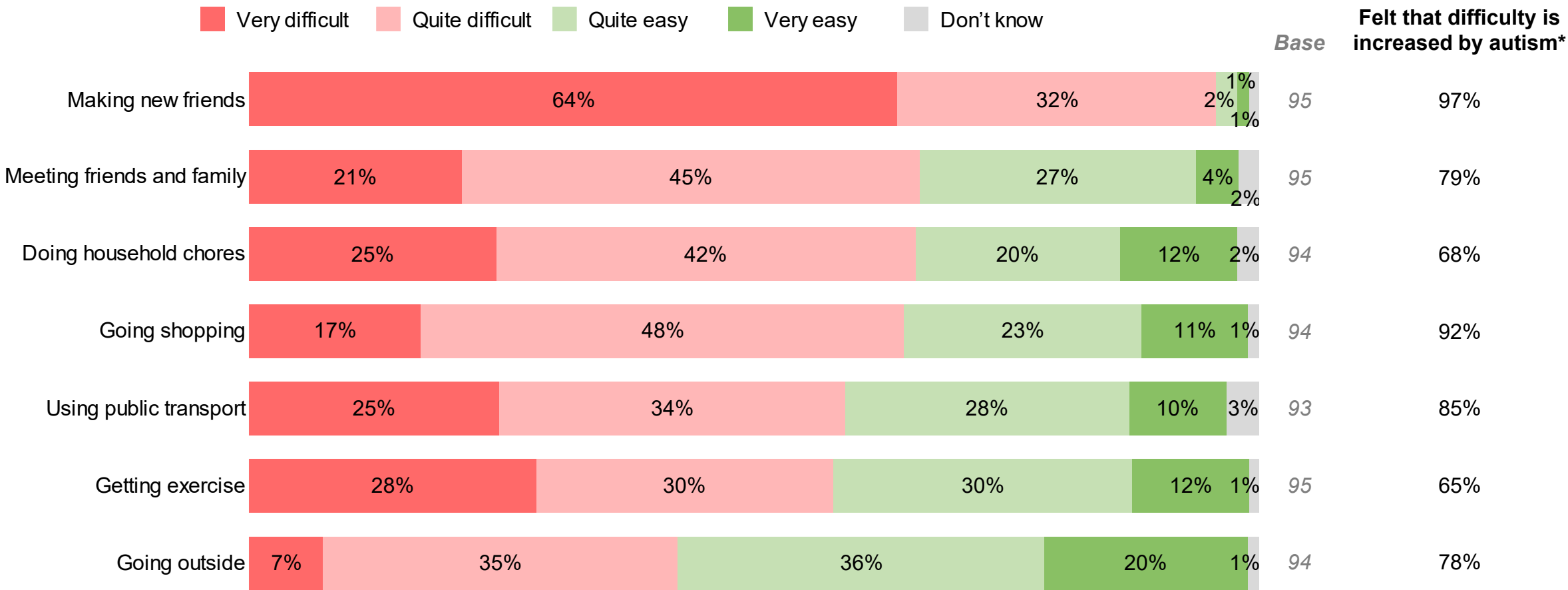
## **Priority 1**

**Improving understanding and acceptance of autism within society**



# Activities undertaken in the community – Making friends was seen as most difficult, with this also most impacted by autism, while difficulties going shopping were also seen to be increased by autism

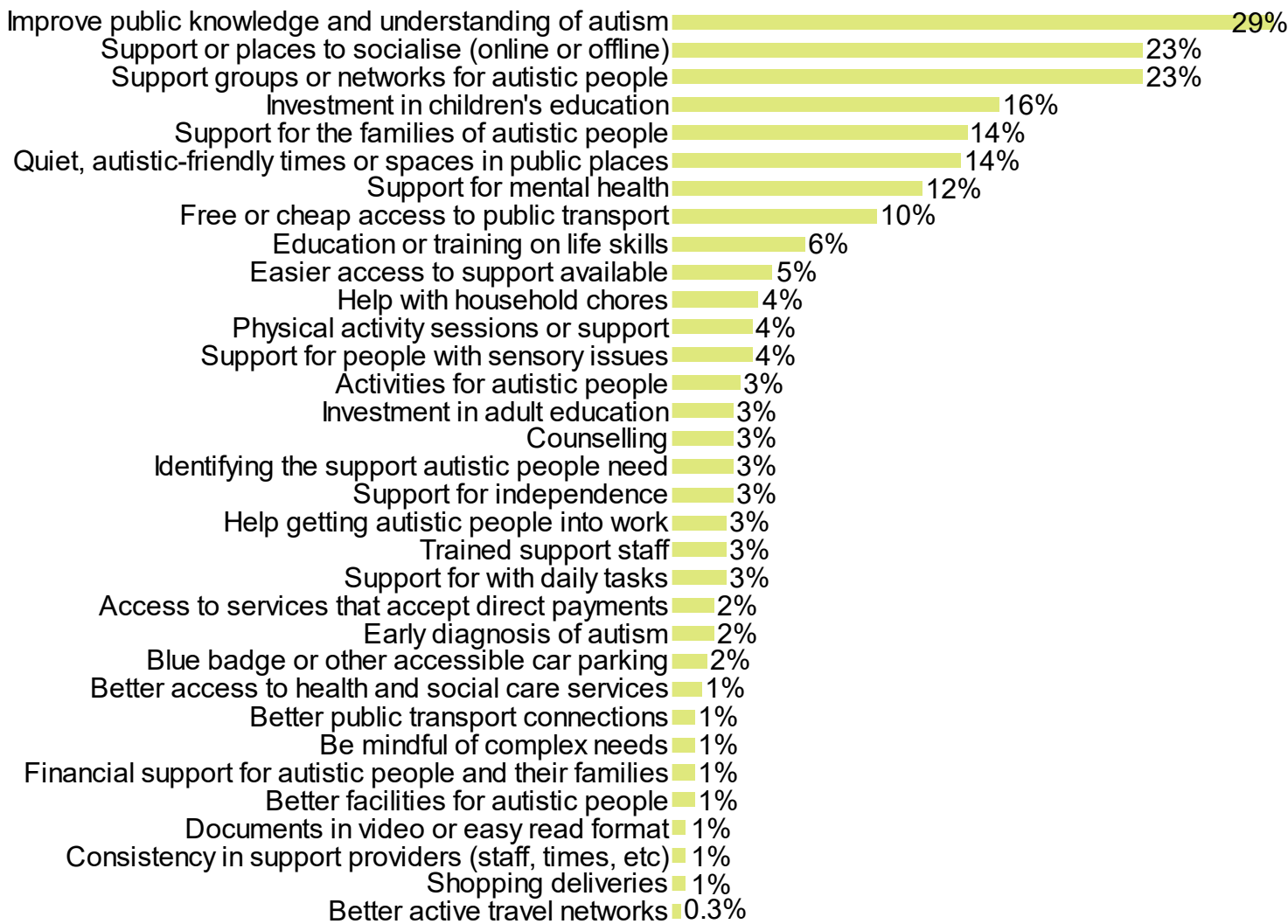
How easy or difficult is...(responses of autistic individuals, ranked by most difficult when ignoring 'Don't know' responses)



\*Of those who responded that this activity is very or quite difficult

# Suggested ways to support activities undertaken in the community

What changes could help autistic people, and those who care for them, to undertake these activities? (Multi-code, base: 314, analysed using an automated text coding process)



The most common suggestion related to improving **the general public's understanding of autism**, to avoid misinterpretation of autistic behaviours as rudeness or misbehaviour, to improve inclusion of autistic people in society, and to encourage the general public to behave in ways less threatening or intimidating to autistic people.

Improving **opportunities to socialise** was also commonly suggested, with views expressed that such support would improve social skills, increase wellbeing, and allow autistic people to gain the confidence to function in society.

**Support groups** were suggested as ways to help autistic people to learn the skills they require for their day-to-day lives as well as improving their understanding of the support available to them.

**Investment in children's education** was proposed as a way to improve the support that children and young people get to live healthy lives, to improve access to extra-curricular activities, and to help educate non-autistic children about their autistic classmates.

Where comments mentioned improving **support for families of autistic people**, this related to improving the quality of existing support such as respite and carer support, and awareness of the support available.

**Autistic-friendly times and spaces in public places** referred to areas such as shops, libraries, and on public transport

# Ways to support activities undertaken in the community – examples of comments

## Improving public understanding of autism

*“Making people more aware of autism would help those with autism feel more comfortable out and about as they won’t feel so judged”*

*“People need to appreciate that autistic people are different and they need to be patient, tolerant and kinder”*

*“Autism awareness courses...should be made available to bus drivers, shop assistants, etc”*

*“...often people assume my daughter is 'naughty' with no boundaries”*

## Opportunities to socialise

*“Providing places where I can meet other autistic adults who struggle with the same issues in a safe environment would really help to know I'm not alone”*

*“It would be nice for them to have somewhere to go to meet other people....but then my son probably would not go! I don't know how to help him make new friends”*

*“More...holiday/weekend clubs will help make friends and being sociable...without parental supervision being required”*

## Support groups

*“Community groups for socialising and sharing advice between peers”*

*“Having more exercise classes that are autism friendly”*

*“My son is desperate to have an after school club like his sisters but the groups are all too large and noisy...It prevents my son being included in the wider community...I believe it to be important for him to learn how to do [day-to-day activities] independently.”*

## Investment in children's education

*“Being taught by teachers that understand the problem autistic children have on a daily basis and are trained to cope with the specific problems autistic children have”*

*“More education in schools so children understand that they need to be patient”*

*“Some of these [life] skills could be included in their education - these would be helpful for those with high functioning autism in a main school setting”*

## Support for families of autistic people

*“More support groups for parents is a big need!!!”*

*“More support in helping families get the right help”*

*“Respite so that I can be a better and less stressed and upset parent”*

*“More day-to-day support for parents of autistic children; particularly those who do not have any other means of support by friends and family”*

*“Coffee mornings to support families”*

## Quiet times and spaces in public places

*“Quiet areas on public transport with personal space protected”*

*“Neurodiverse-friendly cafes”*

*“Autism-friendly shopping hours”*

*“Having quiet hours outside of normal shopping hours dedicated to provide for people with autism and other disabilities”*

*“Quiet times in shopping centres are a welcome step forward but are usually for one hour, at the crack of dawn!”*

# The public's understanding of autism

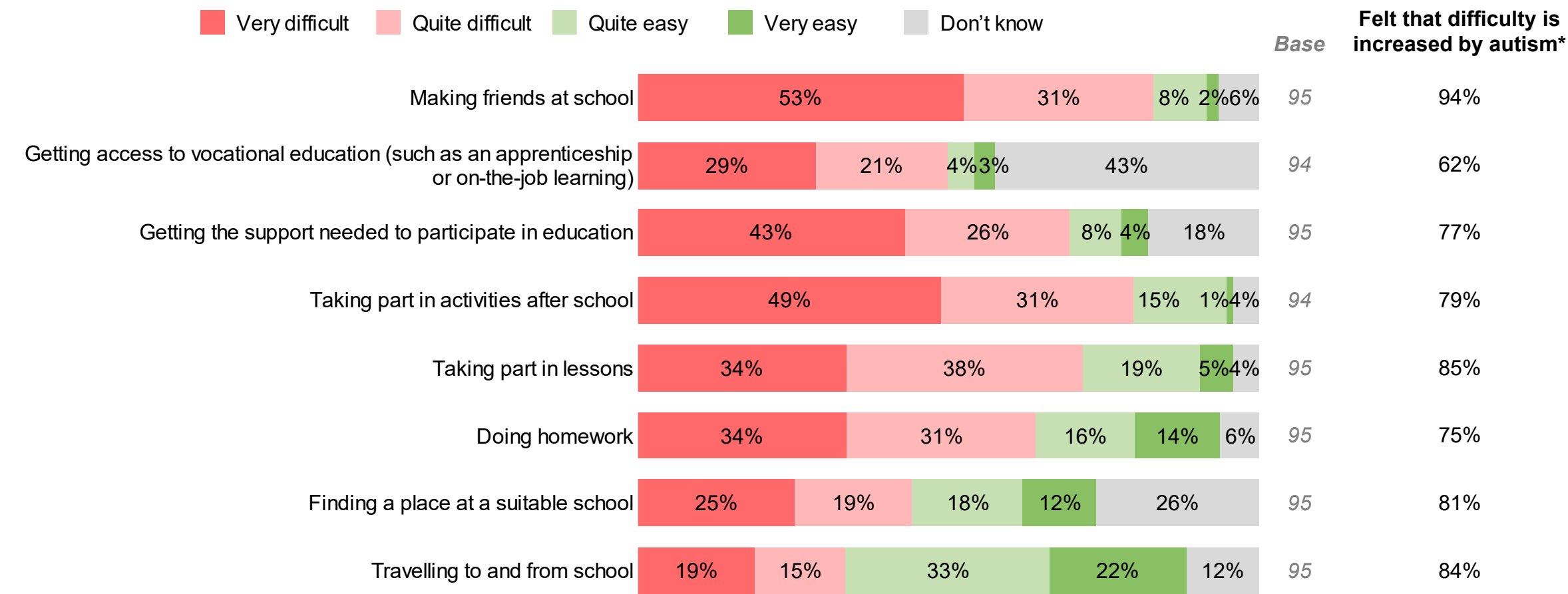
- 95% of respondents felt that the public had a 'poor' or 'very poor' understanding of autism (rising to 98% amongst autistic respondents)
- In addition, 80% of respondents (including 83% of autistic respondents) felt that autistic people were not portrayed accurately in the media. The main reasons for this poor representation included:
  - A poor range of autistic **characteristics and behaviours** shown (41%) *"TV shows only show maybe one aspect of autism, but it's very generalised, and sadly, most of the time, it shows autism in a negative light"*
  - The **accuracy of coverage** of autism in the media (27%) *"It is so overwhelmingly portrayed as being an issue for children, not adults"*
  - The presence of **autistic stereotypes** (29%) and **characters** (17%) in the media *"Autistic people are still portrayed as nerdy savants who have stilted speech and a monotone voice"*
  - The **negative stereotypes** of autism shown in the media (11%) *"The media reports someone has done a crime or something and it will say cause they are autistic, implying the wrong idea that all autistic people will do crime"*
- However, 63% of respondents felt that the public's understanding of autism had improved over the previous five years (including 49% of autistic respondents). When asked to explain why they felt this way, the most common reasons given for this improvement included:
  - There is a changing **public awareness** around autism (49%) *"I think there is more awareness that not all autistic people have the same needs"*
  - **Social attitudes** around autism have changed (23%) *"More accepted and understood now through education. When I was at school it was just a naughty child, no thought of autism"*
  - **Media coverage** of autistic people has improved (21%) *"Celebrities are being diagnosed and talking of their experiences"*
  - The **diagnosis** of autism has improved (16%) *"In my opinion the autism diagnosis has increased significantly over the last 20 years, which has increased public awareness of the spectrum disorder as far more families are touched by this"*
  - There is **more support for autistic people** available (12%) *"Supermarkets and cinemas do sensory mornings / evenings where the lights / music are low"*

## **Priority 2**

**Improving autistic children and young people's access to education,  
and supporting the move from childhood to adulthood**

# Activities undertaken at school – Making friends at school was seen as both the most difficult activity by autistic people, and the activity most impacted by autism

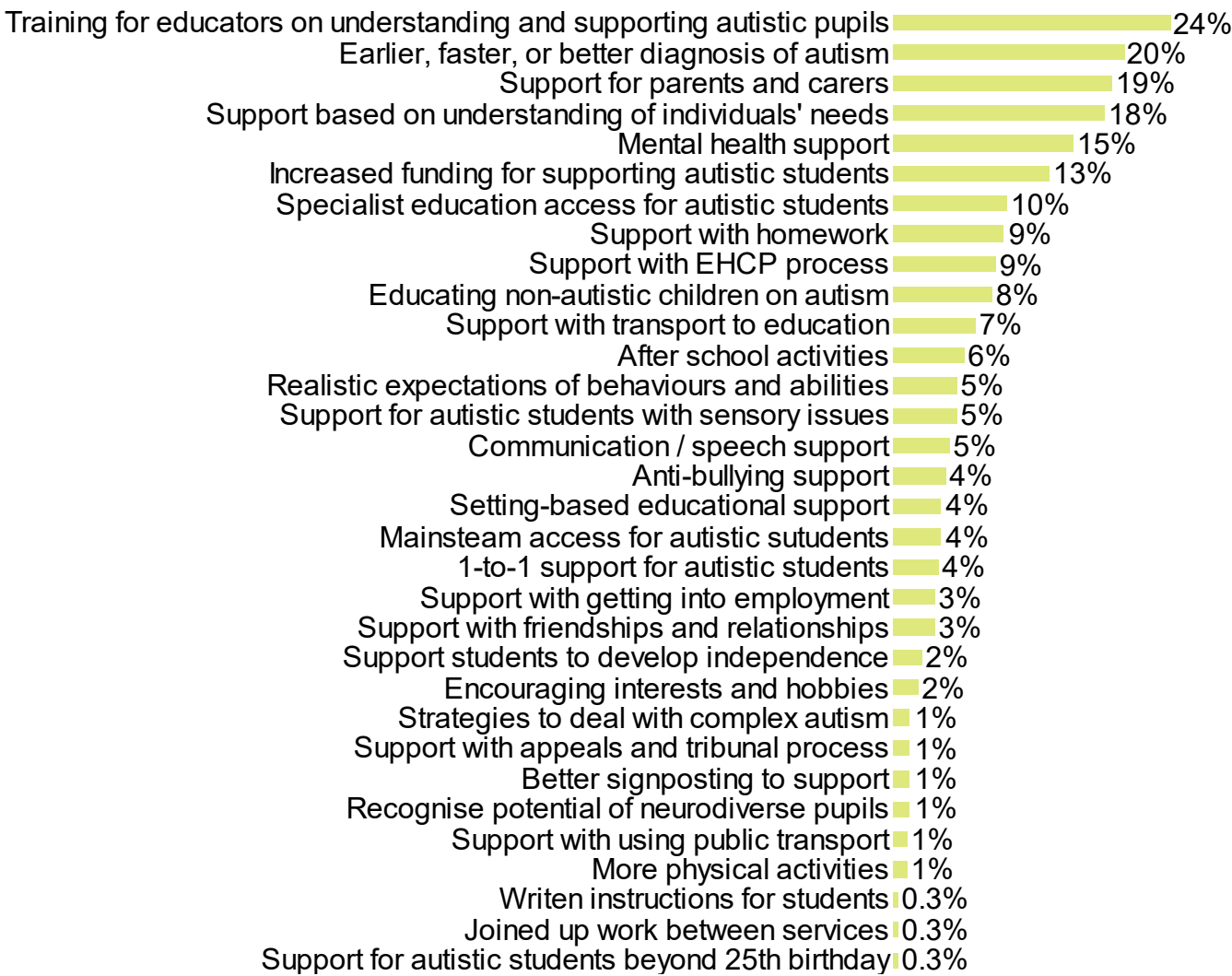
How easy or difficult is...(responses of autistic individuals, ranked by most difficult when ignoring 'Don't know' responses)



\*Of those who responded that this activity is very or quite difficult

# Suggested ways to support activities undertaken at school

What changes could help autistic people, and those who care for them, to undertake these activities? (Multi-code, base: 298, analysed using an automated text coding process)



Respondents most frequently mentioned improving the **skills of educators who work with autistic students**, to ensure that realistic expectations are being placed on autistic students, improving their patience with autistic students, and to help understand how they can support autistic children in their schools.

Improvements to the **autism diagnosis** process were also mentioned, such as by making it faster, easier to access, and simpler for the child and their parents and carers to complete.

Support for **parents and carers** included better signposting to information on the support available, help when in discussions with the local SEN Team, and easy-to-understand guidance on how to support their child's education.

Tailored support based on **individual need** was mentioned in reference to the wide range of behaviours and support needed by neurodiverse children, with some respondents concerned that the support available does not reflect this diversity.

**Mental health** support was mentioned in relation to the need for early intervention and awareness of how everyday situations can overwhelm autistic children, as well as some comments that children can become withdrawn or can suffer mental illness if they do not get the support they need at school.

There were suggestions that **funding** for autistic students be increased, both to reduce pressure on schools' budgets and also to pay for individual therapies and services for autistic students.



# Ways to support activities undertaken at school – examples of comments

## Improving educators' skills

*"More teachers who specialise in autism and all staff to have some sort of understanding and training with autistic children"*

*"School wide comms regarding [autistic students] so that all staff are aware of specific needs, along with education and training in how best to handle an autistic child"*

*"I would try to fit all my homework into my lessons...as I struggled to complete homework outside of school"*

## Improving the autism diagnosis process

*"Our son wasn't diagnosed with autism until he was 25! Doctors and so called experts dismissed our concerns for years"*

*"EHCP process simplified and sped up. taken two years so far and still not sorted meanwhile attendance declining"*

*"The waiting list to have an assessment for diagnosis is over 2 years...in the meantime the child is labelled "difficult or disruptive" and excluded from the classroom environment"*

## Support for parents and carers

*"At present we are trying to obtain the guidance and support we need to assist us with something we know a little about but not enough to ensure we do the best for our family member. It is not apparent where to go to find information and support"*

*"Working parents are penalised by SEN preschool only offering half days"*

*"I never felt anyone listened to our concerns as parents who know our child best"*

## Support based on individuals' needs

*"...schools need to come to grips with...diversity and endeavour to find the best approaches that make learning easy for every individual"*

*"SENCO at my brother's school seemed to have very little understanding of his needs"*

*"Look at the individual and prepare a plan with them involved"*

*"Often autistic individuals are expected to fit into an education system that doesn't work for them"*

## Mental health support

*"We were fortunate to have great ed psychology assessments to aid understanding of our son's needs. My son took two (traumatic) years to settle into secondary school"*

*"Understanding when they feel overwhelmed rather than [being] penalised for non attendance"*

*"More consideration to the learning environment / structure and how it impacts on an autistic child's mental health and ability to learn"*

## Increased funding for autistic students

*"Increase the funds (for EHCP children) in schools (private and state) so that more TAs / LSAs can be hired to support individuals with autism at school and after school with homework tasks and activities"*

*"More funding for 1:1 support is required"*

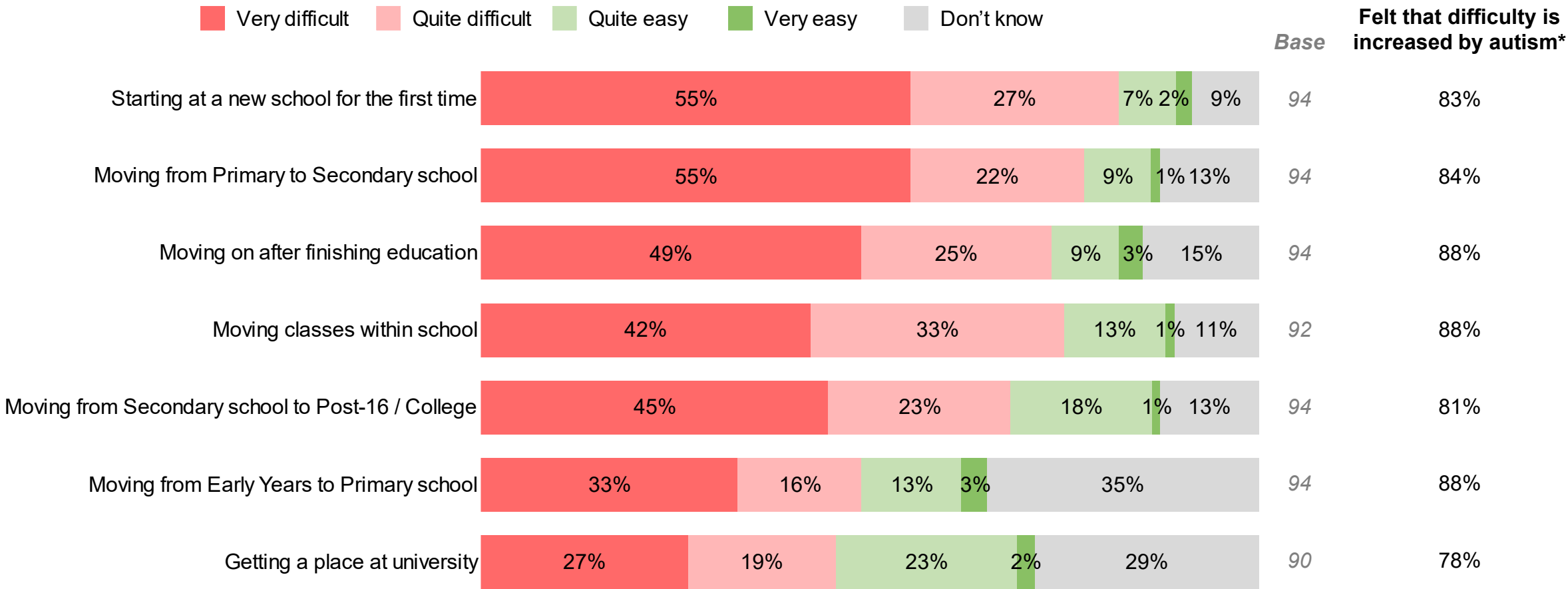
*"Supplying more staff and funds to schools to allow them to meet the needs of the children attending not just those with EHCP's"*

*"More funding to allow LSA support if needed"*



# Transitioning in education – Amongst those with a view, transitioning was seen as difficult in all stages of education, with the large majority feeling that this difficulty is increased by autism

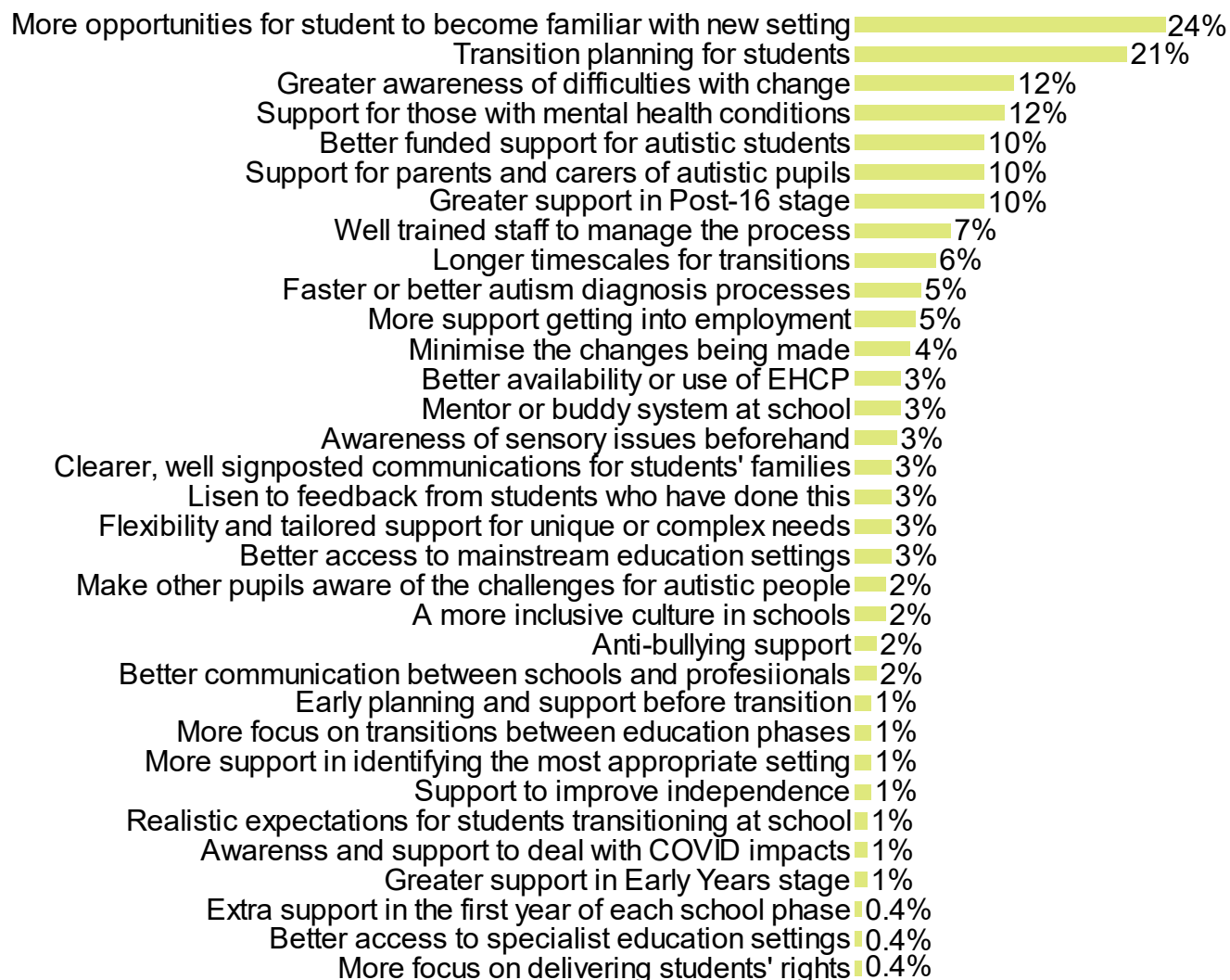
How easy or difficult is...(responses of autistic individuals, ranked by most difficult when ignoring 'Don't know' responses)



\*Of those who responded that this activity is very or quite difficult

# Suggested ways to support transitioning between education phases

What changes could help autistic people, and those who care for them, to make these moves?  
(Multi-code, base: 262, analysed using an automated text coding process)



Comments most frequently mentioned ways to allow autistic students to **become familiar with their new settings**, such as visits, meeting their teachers, and learning their new schedules ahead of their transition.

Suggestions of **transition planning** for students mentioned taking the time to ensure that the change is simple and does not cause autistic students distressed.

Mentions of **difficulties with change** noted that autistic people can struggle with new routines, people, and rules that they are expected to follow.

**Mental health support** mentioned helping with stress and anxiety during the transition process, and the risks of this on autistic students' wellbeing.

Those suggesting **better funded support** for autistic students mentioned more funding for LSAs, SEN support, and the ability to offer tailored support to meet students' range of needs.

Where comments suggested improved **support for parents and carers** this related to clearer communication, involvement of parents and carers in the planning of transitions, and help in locating the most appropriate settings for autistic students.

It was also suggested that transition to **Post-16 education** not be overlooked, and that transition beyond this stage also be supported.

# Ways to support transitioning between education phases – examples of comments

## Opportunities to familiarise with new settings

*“Gving autistic children the opportunity to visit the school before term starts to get used to the layout, smells, sights”*

*“Plenty of visits and support to get to know new staff and to learn their names”*

*“More visits to classroom, spending time with new teacher, more tours of new school, spending time in new school, a map of school and where things are, photo of teacher or staff with names”*

## Planned transitions

*“A longer preparation period should be in place for moving from primary to secondary”*

*“Transition preparation needs to be a huge part of any huge change in the life of someone with autism. A lot of preparation and induction would be required to make the change a success”*

*“The new environment should be prepared and set up with accommodations in advance, rather than seeing what goes wrong and “fixing” things when it’s too late”*

## Greater awareness of issues with change

*“Teachers need to recognise “difficult” behaviour as a cry for help and not a sign of weakness”*

*“I find change very challenging, which causes me to feel anxious. Every time i would change classes / schools I would be going from something familiar to something unfamiliar and it would take me time to observe everything around me, understand the different personalities in the room, and work out how I had to fit in with this new situation”*

## Support for mental health issues

*“More befriending, appropriate spaces to relax and de stress, more pastoral support”*

*“Anxiety for the young person what be a key issue and forward planning for transition might help alleviate the anxiety”*

*“[Change of caseworkers] created anxiety for our son, not helping his need for continuity”*

## Better resourced support for autistic students

*“More funding and easier access to EHCPs and the recommendations being implemented”*

*“Schools should have more staff specifically trained in autism to help those pupils”*

*“Putting people in the right positions who understand the child / individual. A budget for the extras as required”*

## Support for parents and carers

*“Transitions between schools could be improved by better communication between schools involved, parent and young person”*

*“Work with the parents not against them”*

*“Listening to parents/carers when they say all is not well”*

*“...have a few hours with the parent to ask about their child”*

## Support for Post-16 education

*“Support in...making applications to post 16, uni, apprenticeships, etc”*

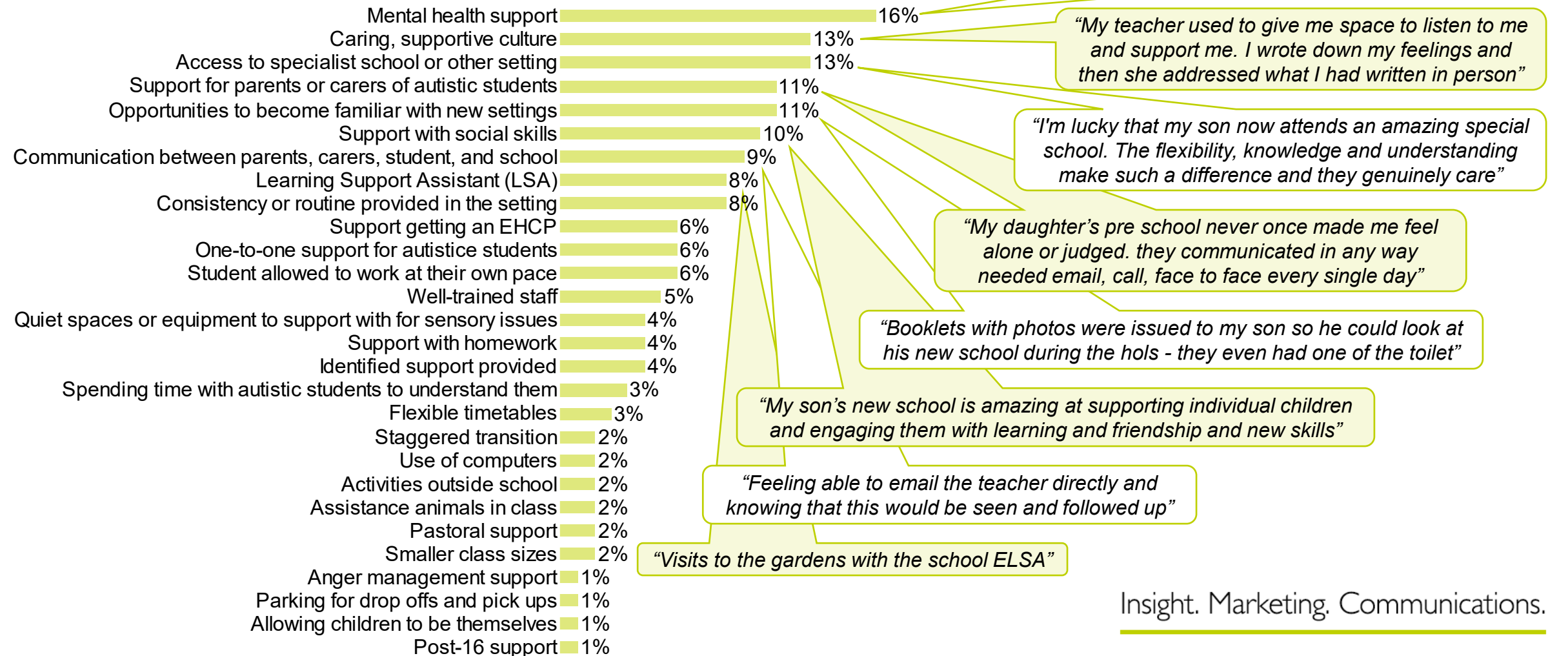
*“All help just stops at 18”*

*“Moving from a secondary setting to college and arranging a [visit] to experience the college can help”*

*“Specialist support for transition from schools..to college”*

# Examples of ways that schools have made education a more positive experience for autistic children and young people

Please share any examples of anything that was done at your school to make education a more positive experience for autistic children and young people (Multi-code, base: 120, analysed using an automated text coding process)

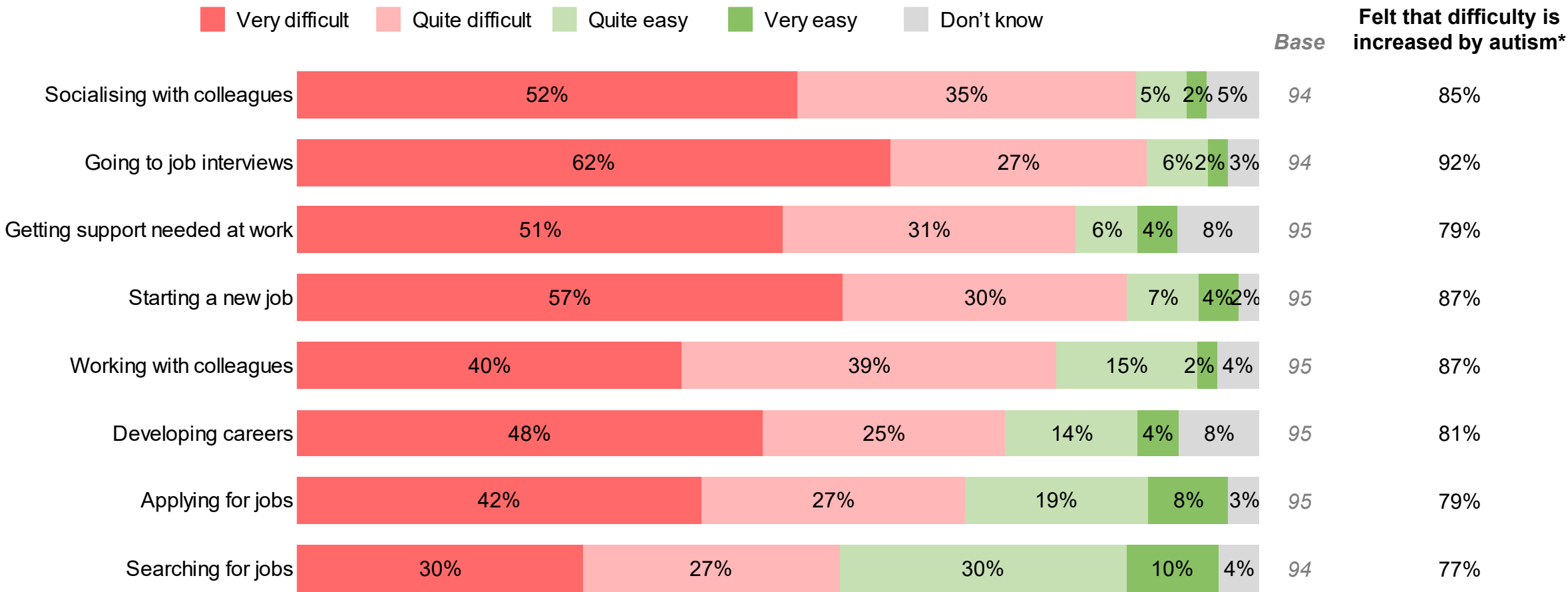


## **Priority 3**

**Supporting more autistic people into employment**

# Employment-related activities – The greatest challenges identified were socialising and attending job interviews, with issues around interviews particularly impacted by autism

How easy or difficult is...(responses of autistic individuals, ranked by most difficult when ignoring 'Don't know' responses)

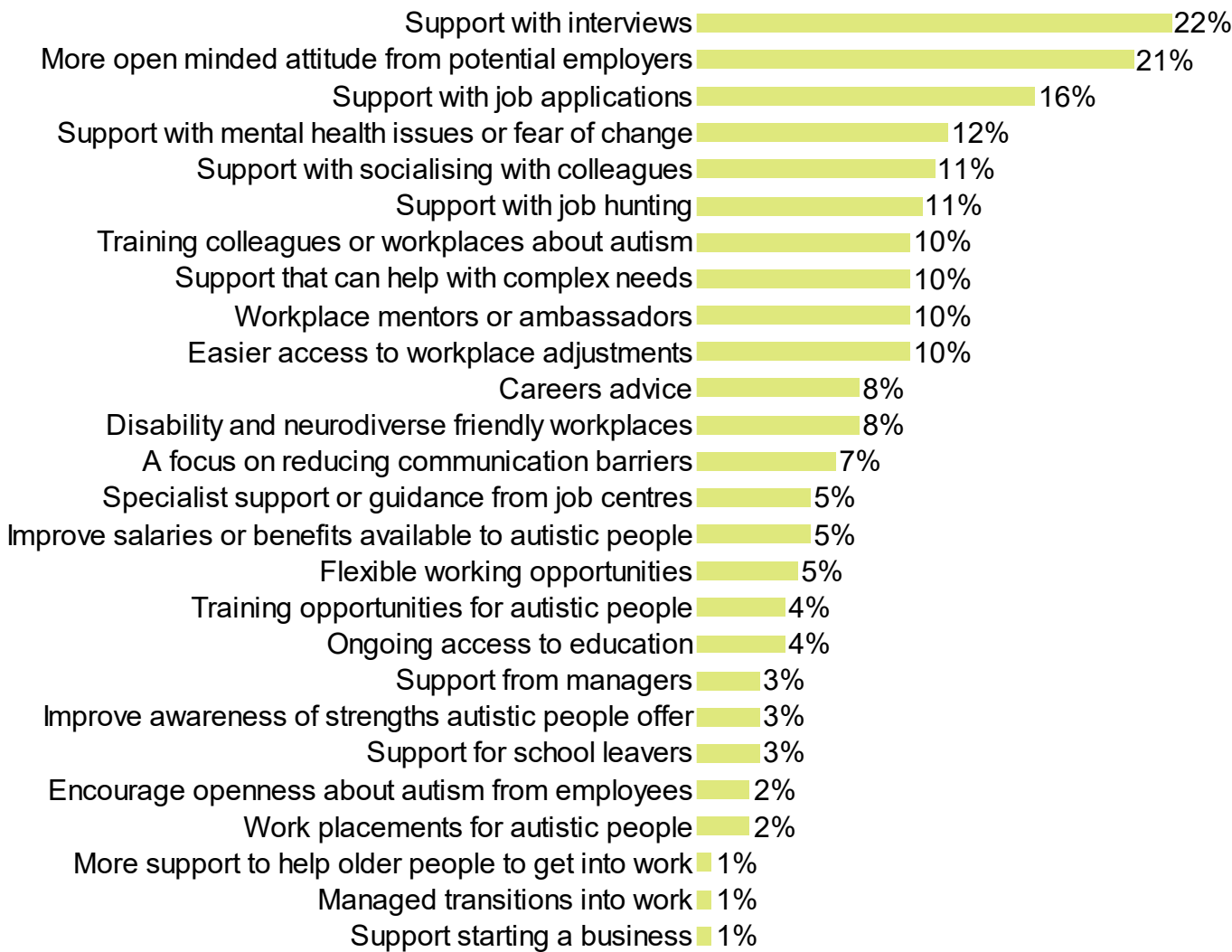


Insight. Marketing. Communications.

\*Of those who responded that this activity is very or quite difficult

# Suggested ways to support autistic people with employment

What changes could help autistic people, and those who care for them, to do these things?  
(Multi-code, base: 170, analysed using an automated text coding process)



The most frequent suggestions for changes related to **interview support**, such as developing skills for taking part in interviews, sharing interview questions with autistic applicants beforehand, and encouraging businesses to be more flexible in how interviews are undertaken (such as online, or in autism-friendly environments).

Suggestions of **improving employers' attitudes to employing autistic people** mentioned that this could be done by improving awareness of the capabilities of autistic people, and the reasonable adjustments that can accommodate them, including how to effectively communicate with autistic people.

Comments also frequently mentioned the issues autistic people have **completing applications**, such as the anxiety it can cause and the difficulty posed by probing questions, as well as a lack of clarity in the application process about job requirements and the environments in which applicants would be expected to work.

Where **mental health or fear of change** were mentioned, this regularly related anxiety autistic people face when entering new environments, and the benefits of job centre employees being aware of the concerns that autistic people have about finding employment.

Support with socialising with colleagues mentioned that workplaces could plan team building activities to be autism-friendly, and that lack of socialising can have mental health impacts.



# Ways to support autistic people in employment – examples of comments

## Support with interviews

*“Autistic people get so anxious and would perhaps not attend an interview on site so perhaps could be conducted in a more friendly familiar place ie a cafe or home”*

*“Unless interviewers are educated and know the many benefits of having an employee on the spectrum, and are aware of my many daily struggles, then I may as well talk to a brick wall”*

*“Virtual interviews, I have found, are much easier as they involve less personal preparation”*

## More open minded attitude from potential employers

*“...after many years of difficulty I found an employer who were actively prepared to work with our autistic son and from an employment point of view it has been a success”*

*“Employers seem to not look at what an autistic person can do but rather what they can't do”*

*“I've had my first job in 17 years for a year now, I work part time with an autism charity and they are very understanding”*

## Support with job applications

*“I would take things too literally and assume everything in the advert was an essential requirement for the role, so I would be reluctant to even try applying for some jobs as I always thought i was underqualified or inexperienced. it would have helped if I'd realised/been told earlier that a lot of the content on job adverts are desirable but not required”*

*“Simply applying for jobs can send autistic people into a spiral of self-doubt and paralysis”*

## Support with mental health issues or fear of change

*“They will need support in order to keep a job and maintain a job due to the pressure of working responsibilities”*

*“Being not understood at work is exhausting”*

*“...there have been a few times where i've had a meltdown on my first day for not understanding the tasks I have been given...and feeling 'thrown in the deep end' without support from a peer, manager, 'buddy', or mentor”*

## Support with socialising with colleagues

*“I do love making friends and having friends, but I find it so difficult to maintain relationships because the way I show friendship is different to other people...I often feel very lonely!”*

*“I have a successful career but I'm a loner and can't socialise. I would like to be able to do that.”*

*“Socialising is very challenging, particularly with work colleagues as it is a change in environment and a change of "style" from how I would usually interact with these people”*

## Support with job hunting

*“Ensuring that job centres understand autism and the anxieties that go with the condition. Often autistic people can stress over the smallest thing and this can be prohibitive to them moving through the above stages. Therefore, time is needed to reassure them and move through the stages at their pace”*

*“There need to be career advisors and support services with staff trained in supporting young people with autism”*

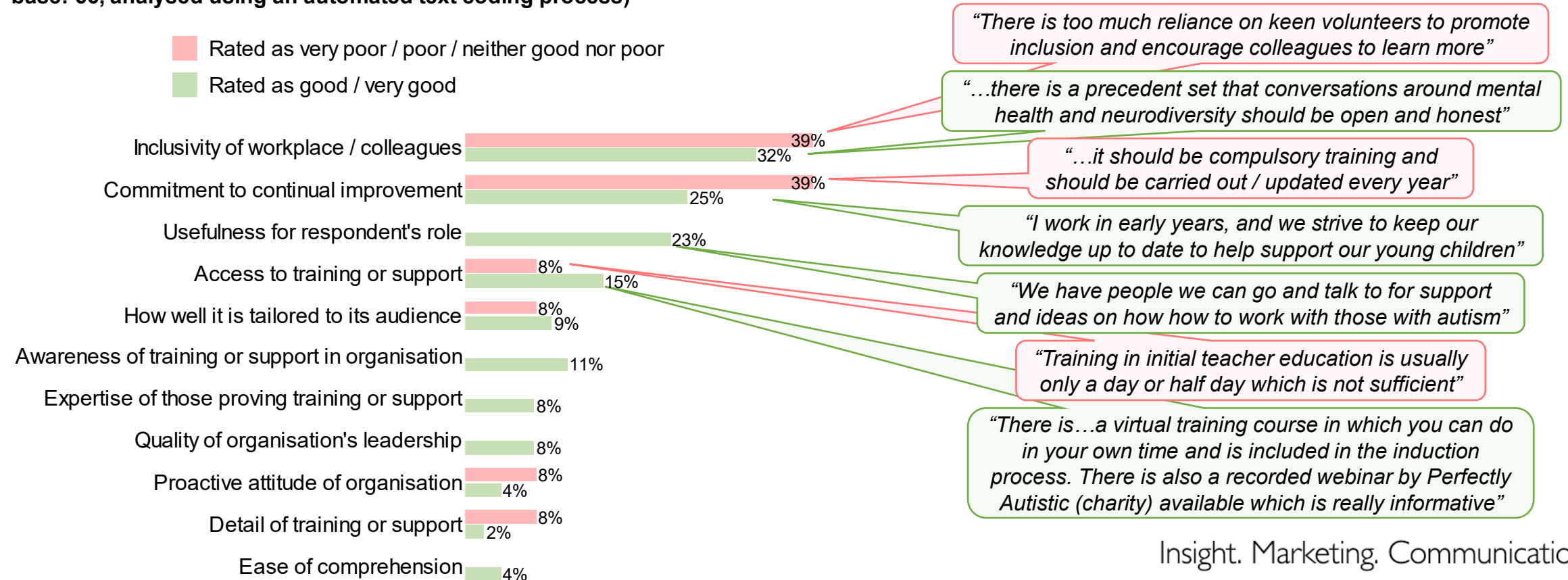


# Training and support to improve inclusion for autistic people in the workplace – Where available, this is generally seen as being of a good quality, with frequent reference to inclusivity and continual improvement

53% of respondents who had knowledge of it said that their organisation provided training or support to help autistic people be more included in the workplace, although only 37% of autistic people felt this way

Of those aware of such training in their organisation, 79% said it was 'good' or 'very good' (81% of autistic people)

**Please explain why you gave the training or support this rating (Multi-code, base: 66, analysed using an automated text coding process)**



## **Priority 4**

**Tackling health and care inequalities for autistic people**

**Health-related activities** – While the most difficult activities were seen to be getting an appointment for an autism assessment or a mental health referral, autism was said to have the most impact on people's ability to understand information provided to them and attend healthcare appointments

How easy or difficult is...(responses of autistic individuals, ranked by most difficult when ignoring 'Don't know' responses)

■ Very difficult  
 ■ Quite difficult  
 ■ Quite easy  
 ■ Very easy  
 ■ Don't know

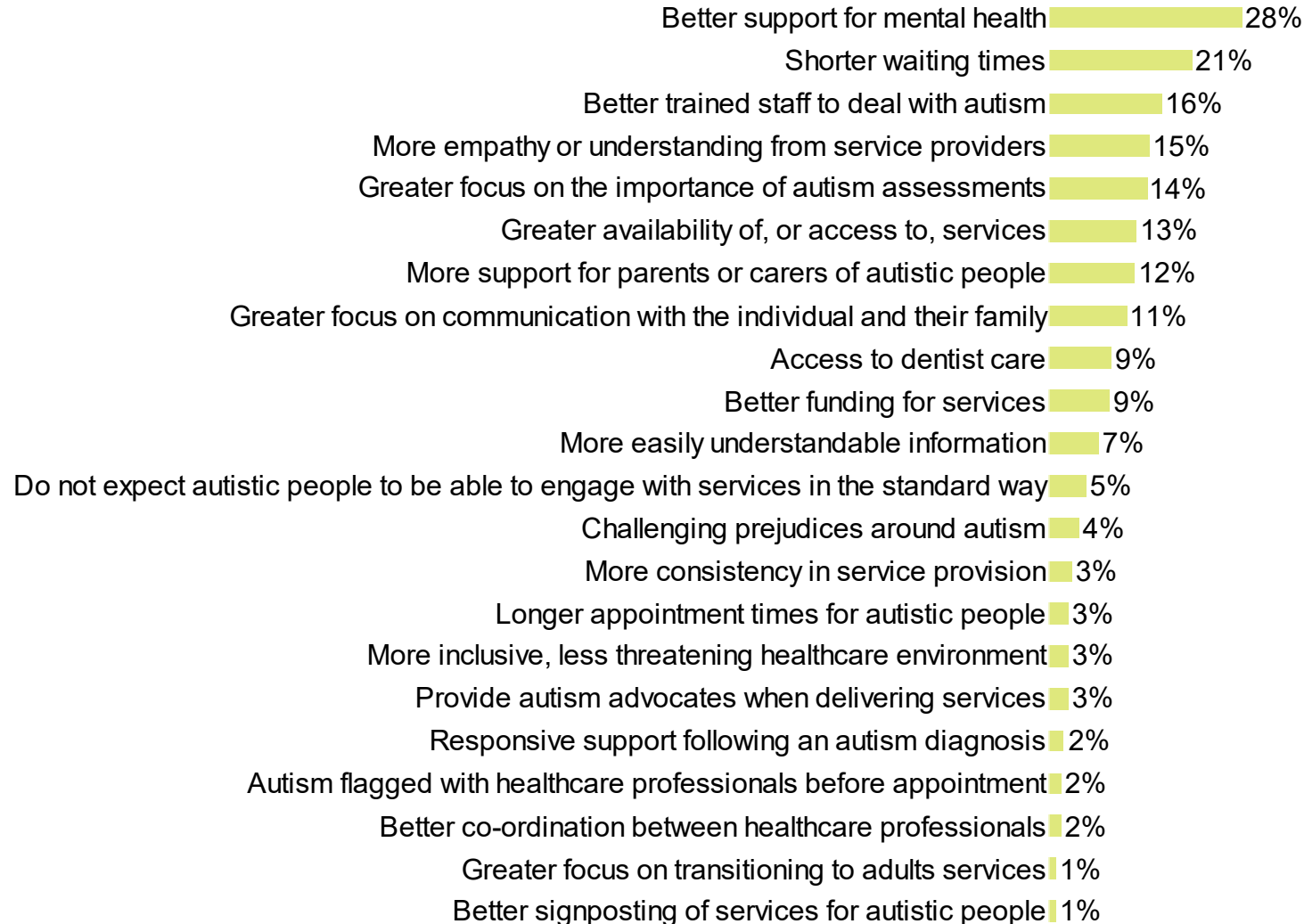
						Base	Felt that difficulty is increased by autism*
Getting an appointment for an autism assessment	61%	14%	8%	2%	15%	95	61%
Being referred to a specialist for mental health needs	53%	20%	10%	2%	15%	94	71%
Getting all of the medical treatment that is needed	38%	35%	13%	2%	12%	94	68%
Being understood by doctors and other healthcare providers	47%	25%	14%	4%	10%	95	78%
Being referred for an autism assessment	52%	17%	17%	3%	12%	95	68%
Getting an appointment with a GP	43%	27%	20%	7%	3%	93	58%
Being referred to a specialist for physical health needs	32%	28%	19%	4%	17%	94	57%
Being believed by doctors and other healthcare providers	38%	21%	17%	8%	16%	95	71%
Getting health advice (including 111, A&E, etc)	23%	34%	27%	5%	11%	93	64%
Attending an autism assessment	23%	26%	21%	10%	20%	95	79%
Attending healthcare appointments	26%	33%	32%	7%	2%	93	85%
Being treated respectfully by doctors and other healthcare providers	28%	24%	22%	13%	13%	95	78%
Getting an appointment with a dentist	32%	26%	33%	7%	2%	93	56%
Getting registered with healthcare services (GP, dentist, etc)	21%	25%	32%	8%	14%	95	61%
Understanding the information provided by doctors and other healthcare providers	20%	31%	32%	14%	4%	95	88%

Insight. Marketing. Communications.

\*Of those who responded that this activity is very or quite difficult

# Suggested ways to support autistic people with healthcare-related tasks

What changes could help autistic people, and those who care for them, to do these things?  
(Multi-code, base: 269, analysed using an automated text coding process)



Comments most commonly mentioned a perceived need for better **mental health support**, with frequent mention of support for younger people and a lack of awareness of mental health needs amongst healthcare workers.

**Waiting times** were mentioned in relation to autism assessments and for the support required by autistic people, with comments that this has become more difficult since the COVID pandemic.

Suggestions of **better training for healthcare staff** to support with autism related to improving awareness about autism amongst healthcare professionals, improving their ability to recognise the symptoms of autism, and helping healthcare staff to better communicate with autistic people.

Where respondents commented **that healthcare providers should be more understanding of autistic people**, this regularly related to feelings that autistic people and their families were not believed by healthcare professionals, and where staff did not appear to recognise the distress that autism experienced during medical appointments.

Healthcare services recognising the **importance of autism assessments** was highlighted as a way to ensure that autistic people could access the services they required more quickly, as well as providing autistic people, their parents, and their carers with recognition of the individual's autism.

# Ways to support autistic people with healthcare-related tasks – examples of comments

## Better support for mental health

*"The length of time of getting an assessment causes anxiety in itself and not knowing when the appointment will be"*

*"Autistic people, especially those classed as 'high functioning' often mask their discomfort and difficulties in order to 'pass' as neurotypical. this leads to internalised feelings of being an outcast/wrong/inadequate which often leads to cripplingly low self-esteem and high risks of self-harm and suicide"*

## Shorter waiting times

*"I have been waiting for a CAMHS assessment for mental health (linked to autism) and have waited 9 months so far with no expected appointment date"*

*"Increase the number of autism assessments to reduce the waiting time from being referred to being assessed"*

*"The waiting list for an autism assessment appointment is on average two years. Due to the pandemic I waited almost five"*

## Better trained staff to deal with autism

*"Doctors should have more autism awareness and more understanding when we struggle to communicate"*

*"NHS staff have little understanding of the complexity of severe autism. They regularly expect me to restrain my son so they can examine him etc which is distressing"*

*"Training on how to explain medical terms to autistic people"*

## More empathy or understanding from service providers

*"I sometimes find the language used can be quite derogatory"*

*"Many doctors and dentists are very kind to me. But before I was diagnosed with autism, i was referred to psychiatrists who had a poor understanding of autism: when I spoke of my suspicion that i could be autistic, he rapidly replied that it's not possible because I don't flap my hands!"*

## Greater focus of the importance of autism assessments

*"Diagnoses is key to help and support a person who has autism"*

*"Assessment definitely means the school gives more support"*

*"We are ...finding the money to try and get [my daughter] a private diagnosis in order for her to get the understanding and support she needs to get through secondary [school]"*

## Greater availability of, or access to, services

*"Please increase the number of NHS dentists. Many autistic people rely on NHS healthcare and do not have dentists as there are no NHS dentists taking new patients"*

*"The individuals i work with really struggle to be heard and to get any support from health as services are so stretched"*

*"[There should be] doctors and other specialists who are specifically ring fenced for the care of the autistic"*

# Experiences of autism assessments

## Use and importance of autism assessments

- 350 respondents (of whom 75 were autistic themselves) had, or knew somebody who had, received an autism assessment
- Autism assessments were seen as important to respondents primarily to help get educational support (82%), to help parents and carers understand an autistic child (69%), and to recognise the concerns parents and carers may have about a child's behaviour (63%)
- In contrast, for autistic people the most important benefits of autism assessments given were to access support at work (74%), to confirm autism for a person they know (66%), and to protect them from discrimination (62%)

## Access to autism assessments

Of the respondents who had experienced autism assessments, where they expressed an opinion on access to them:

- 76% found it 'quite difficult' or 'very difficult' to be **referred for an autism assessment** (78% of autistic respondents)
- 80% found it 'quite difficult' or 'very difficult' to **get an appointment for an autism assessment** (83% of autistic respondents)
- 52% found it 'quite difficult' or 'very difficult' to **attend an autism assessment** (62% of autistic respondents)

## Feedback on autism assessments

Of the respondents who had experienced autism assessments who expressed an opinion on their quality and value:

- 88% found them **useful for the person being assessed** (93% of autistic respondents)
- 86% found them **of a good quality** (89% of autistic respondents)
- 84% found them **detailed** (87% of autistic respondents)
- 62% found them **understandable for the person being assessed** (80% of autistic respondents)
- 25% found them **quick** (28% of autistic respondents)

## Communication of information around autism assessment

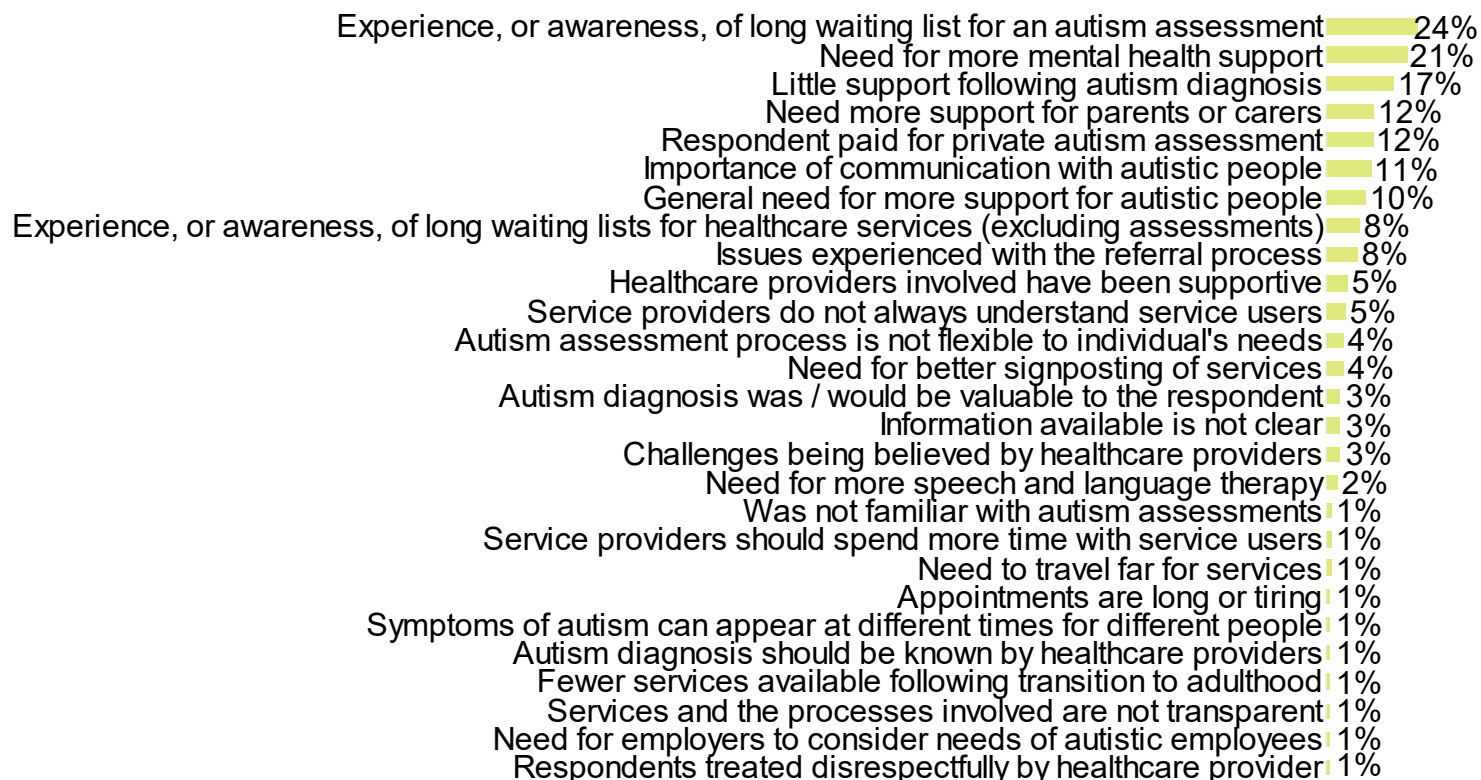
Of the respondents who had experienced autism assessments who expressed an opinion on access to the communication of them:

- 68% found the information provided **before the assessment** clear (65% of autistic respondents)
- 83% found the information provided **during the assessment** clear (85% of autistic respondents)
- 72% found the information provided **after the assessment** clear (68% of autistic respondents)

# Experiences of waiting times and additional comments on access to healthcare

- 44% of those who had a view on the matter felt that **waiting times** were longer for autistic people than for other people, compared with 1% who felt they were shorter for autistic people (responses from autistic people were similar at 45% and 1% respectively)
- Where respondents shared additional views on access to healthcare for autistic people, these most commonly related to experiences or knowledge of long waiting times for autism assessments (24%), a perceived need for more mental health support (21%), and for more follow-up support to be available following an autism diagnosis (17%)

## Additional comments about the healthcare experiences of autistic people (Multi-code, base: 219, analysed using an automated text coding process)



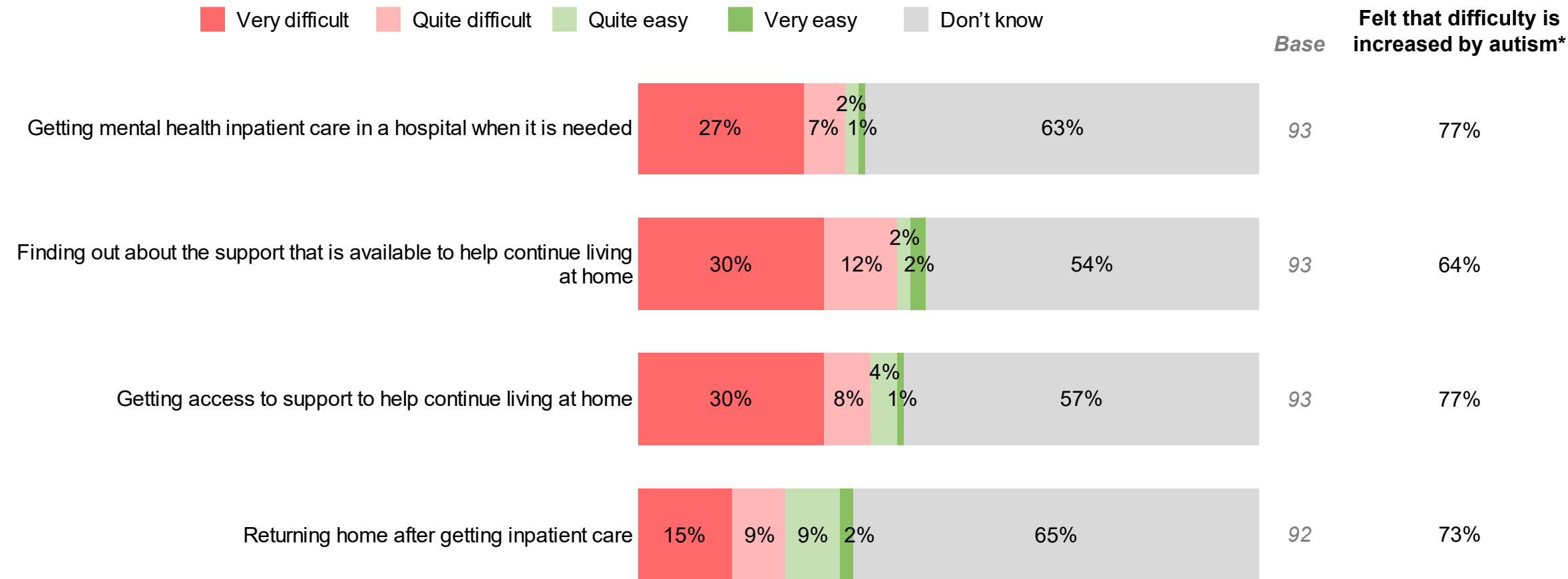
## **Priority 5**

**Building the right support in the community and supporting people receiving care**



# Support in the community – Autism was seen to be a greater barrier to getting support that was needed than to finding out about the support available

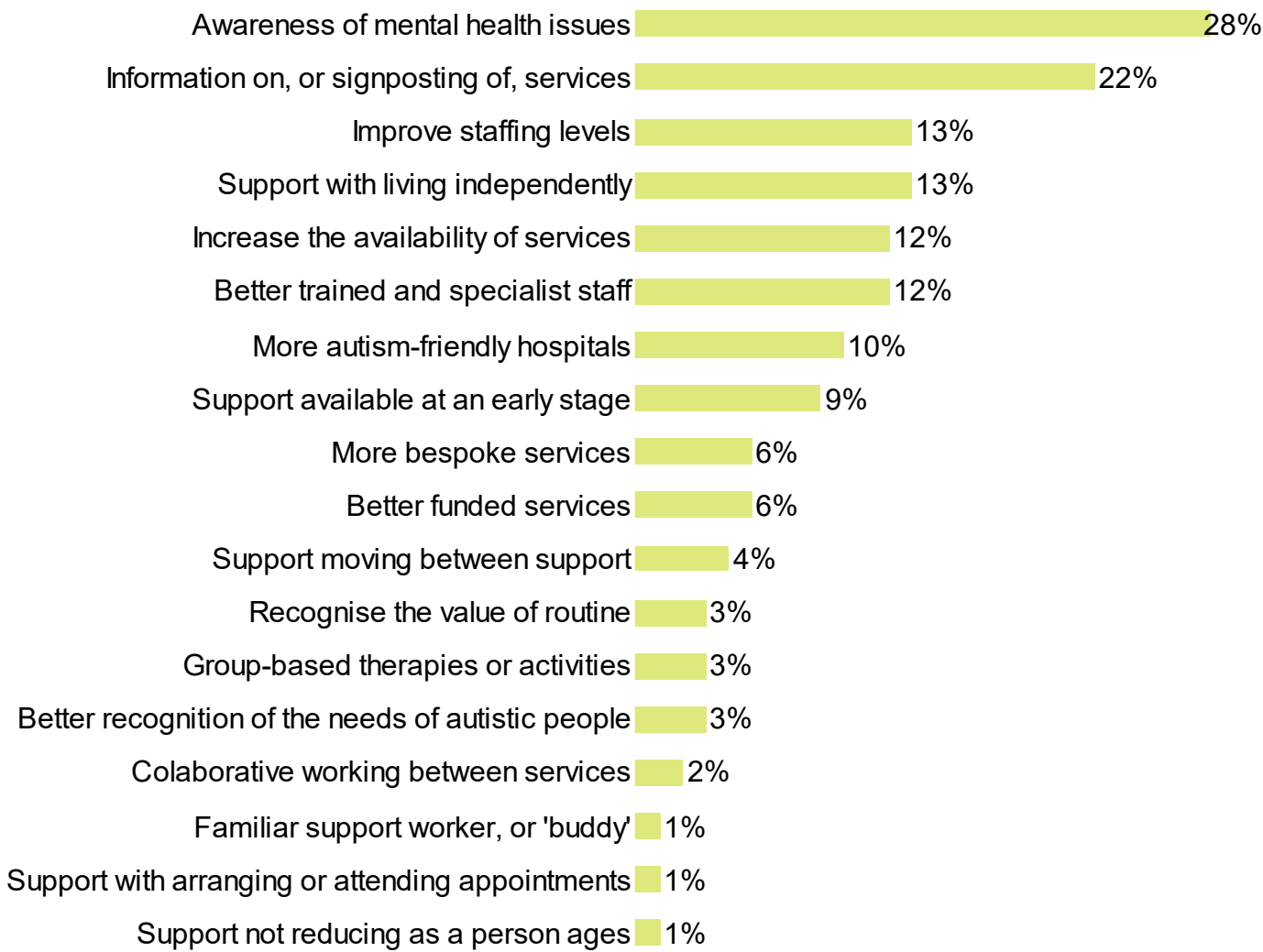
How easy or difficult is...(responses of autistic individuals, ranked by most difficult when ignoring 'Don't know' responses)



\*Of those who responded that this activity is very or quite difficult

# Suggested ways to improve support in the community

What changes could help autistic people, and those who care for them, to do these things? (Multi-code, base: 91, analysed using an automated text coding process)



Almost three in ten responses referred to the need for services to understand the impacts of **mental health** issues on autistic people and respond effectively to these.

Respondents also frequently mentioned the need for better **information on services** and where to find them.

Suggestions for improved **staffing levels** referenced that some services had insufficient staff, or that numbers had reduced over previous years.

Where respondents referred to **independent living**, this was in relation to giving autistic people the opportunities to live in accommodation without a carer, as well as helping them to develop the skills needed to live independently.

There were comments about **service availability**, both in reference to issues accessing services, and waiting times to do so, as well as views that the community services needed were unavailable in Hampshire.

Comments about **staff training** suggested that staff be trained to provide the support that autistic people require, as well as ensuring that the support provided is administered by professionals with a deep understanding of issues around autism.

## Suggested ways to improve support in the community – examples of comments

### Awareness of mental health issues

*“Easier access to counsellors to help with day to day living and reduce anxiety”*

*“I have experience of an autistic friend who experienced autistic burnout and ended up in an psychiatric unit. She was poorly treated and twice admitted and then discharged a day or so later despite no appropriate care in place, she ended up self harming very badly and then ended up in prison as she did not feel safe being alone at home - so offended to get into prison!”*

### Information on, or signposting of, services

*“There is support...and often you don't hear of it by professionals it's normally through friends or other people”*

*“We only became aware that we qualified for carer's allowance in a casual conversation with another parent”*

*“We didn't know about any if the support available for about 2 years after diagnosis. It would have been great if that was clearer”*

### Improve staffing levels

*“Staff turnover in social services means that we only ever get as far as assessments rarely moving on to planning care and support needs”*

*“[Autistic people need] someone to talk to who understands whenever it's needed”*

*“All families should be allocated a support worker to help them begin their journey and information about strategies”*

### Support with living independently

*“Once help was granted it was finally good to see my sister get help in the home to stay at home. She tried independent living for a while but this lead to very poor mental health”*

*“Classes and support to enable the autistic person to develop their self care skills so they can become independent”*

*“More facilities to help support employment / living independently. These appear to have disappeared over time”*

### Increase the availability of services

*“On paper the support is offered but in reality it never materialised. We are both physically disabled too and have been trying to get help at home for years”*

*“Support should be available to all without means testing”*

*“Currently have no support whatsoever but daughter needs round the clock support”*

### Better trained and specialist staff

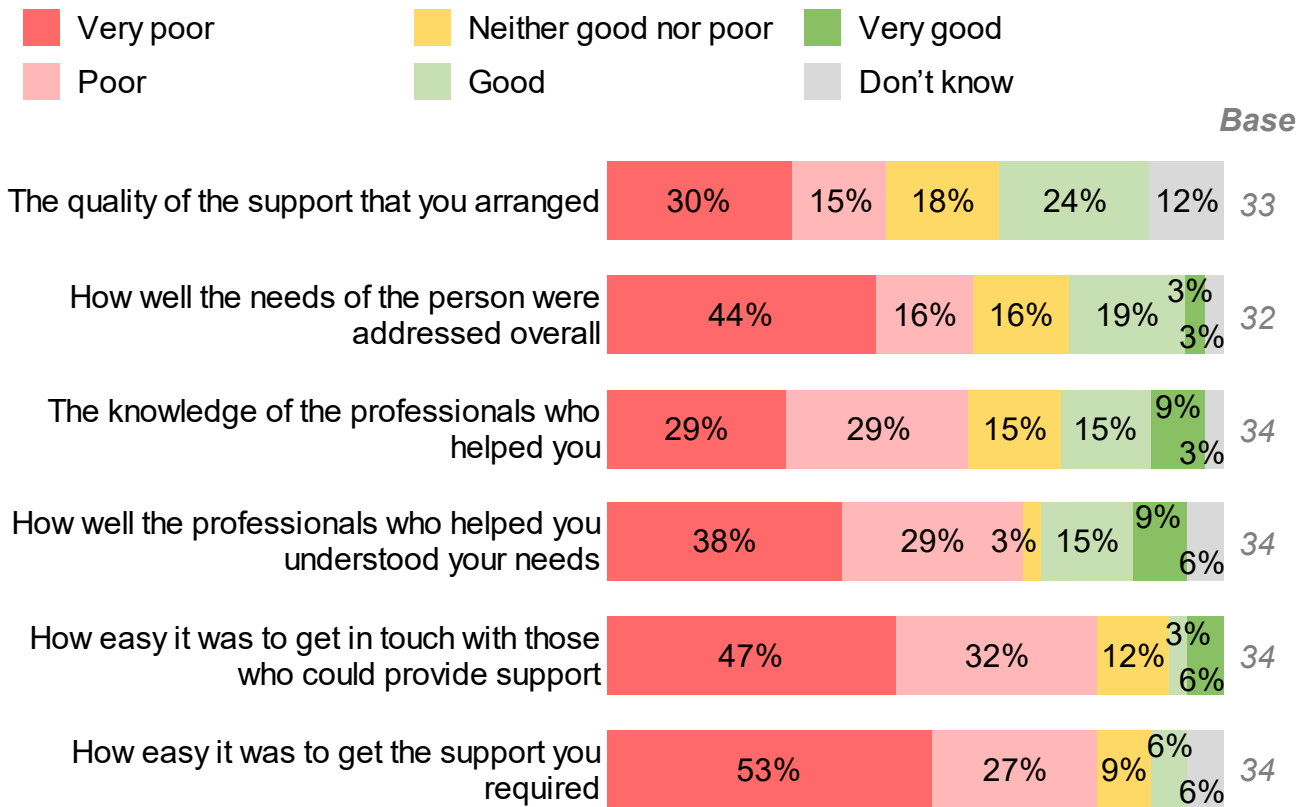
*“More training for the medical staff as the majority don't understand autism and all its nuances. Additionally, as they are so busy, they see an autistic person as a problem and are thus unable to deal with them properly”*

*“[Autistic people and their families] need access to highly trained and competent staff members who have a secure understanding of how to support during these situations”*

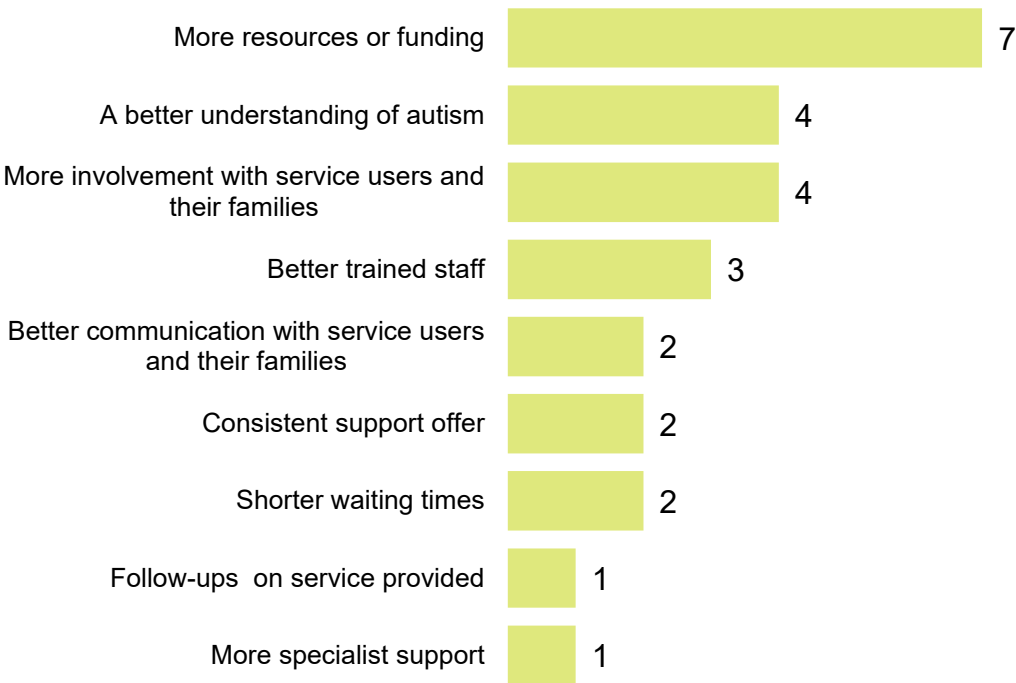
# Arranging support to help autistic people remain in their homes - Issues relating to access seem to be a greater concern than the quality of support available, although feedback from the relatively small number of responses on this subject suggested that there could be issues in all areas

Of the 34 respondents who had arranged support for an autistic person to live in their home...

## Thinking about the last time you arranged support, how would you rate...?

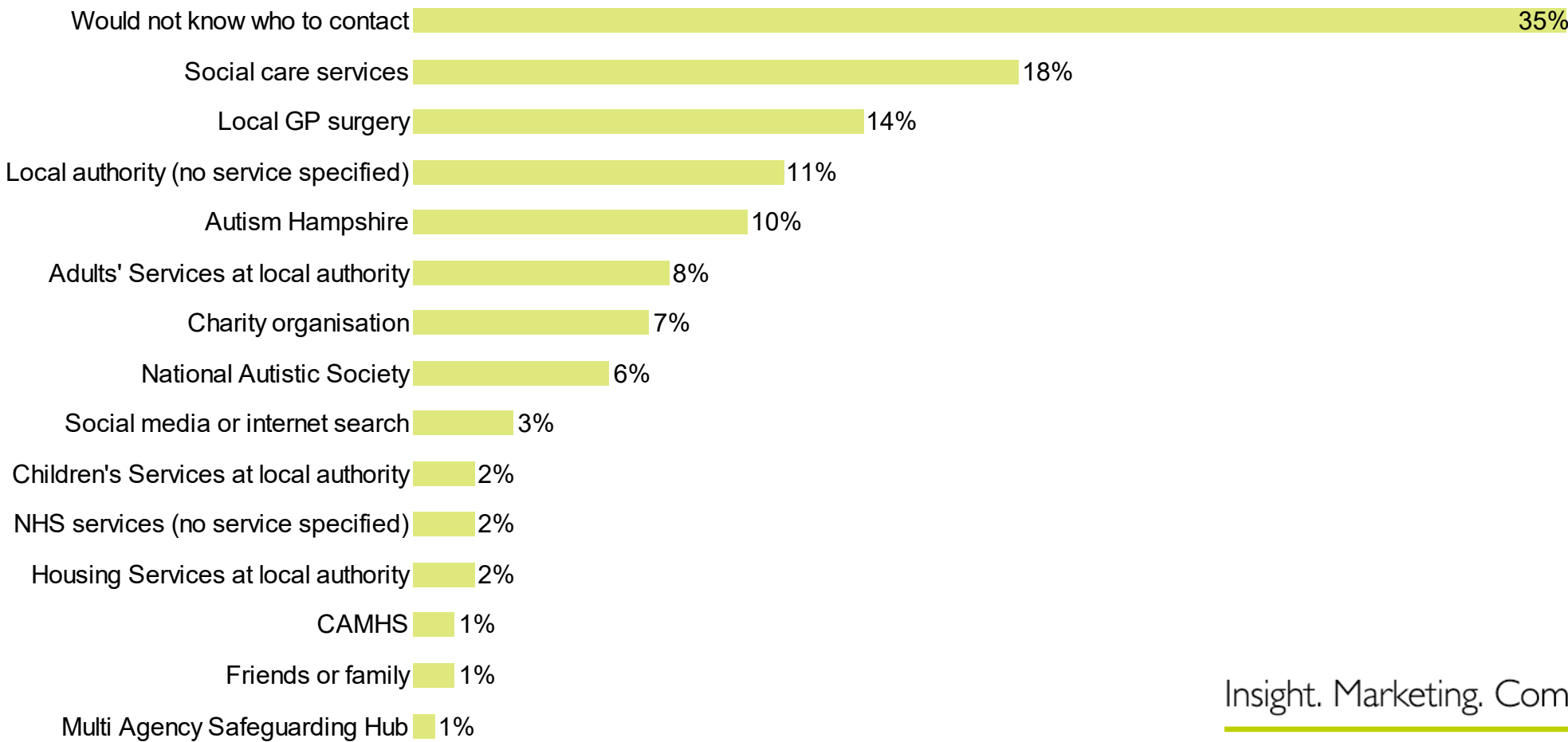


## What improvements would you suggest (Multi-code, base: 22)



**Arranging support to help autistic people remain in their homes** – Among those who had never arranged such support, a third had no idea of whom they would contact. Social care, local GP surgeries, and local authority services were seen as the most likely contacts by those who had a view

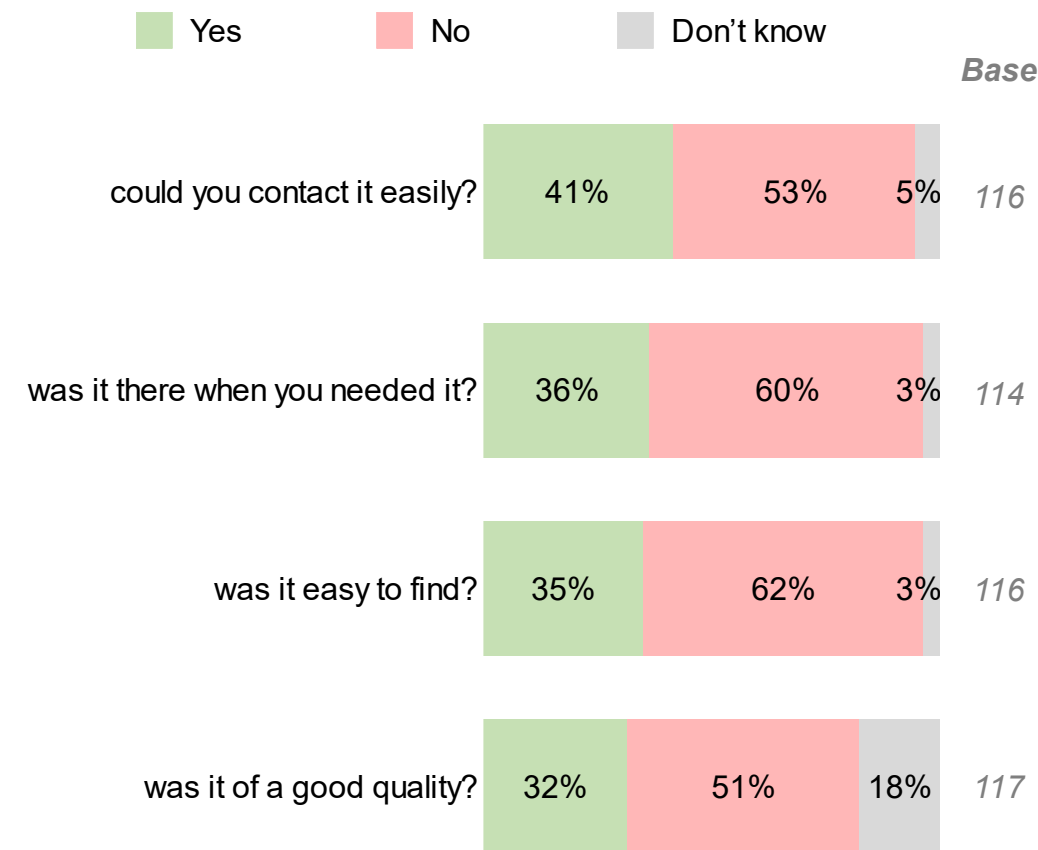
If you were looking for advice or support to help an autistic person to stay in their home, who would you contact first? (Multi-code, asked to those who had not previously arranged such support, base: 169, analysed using an automated text coding process)



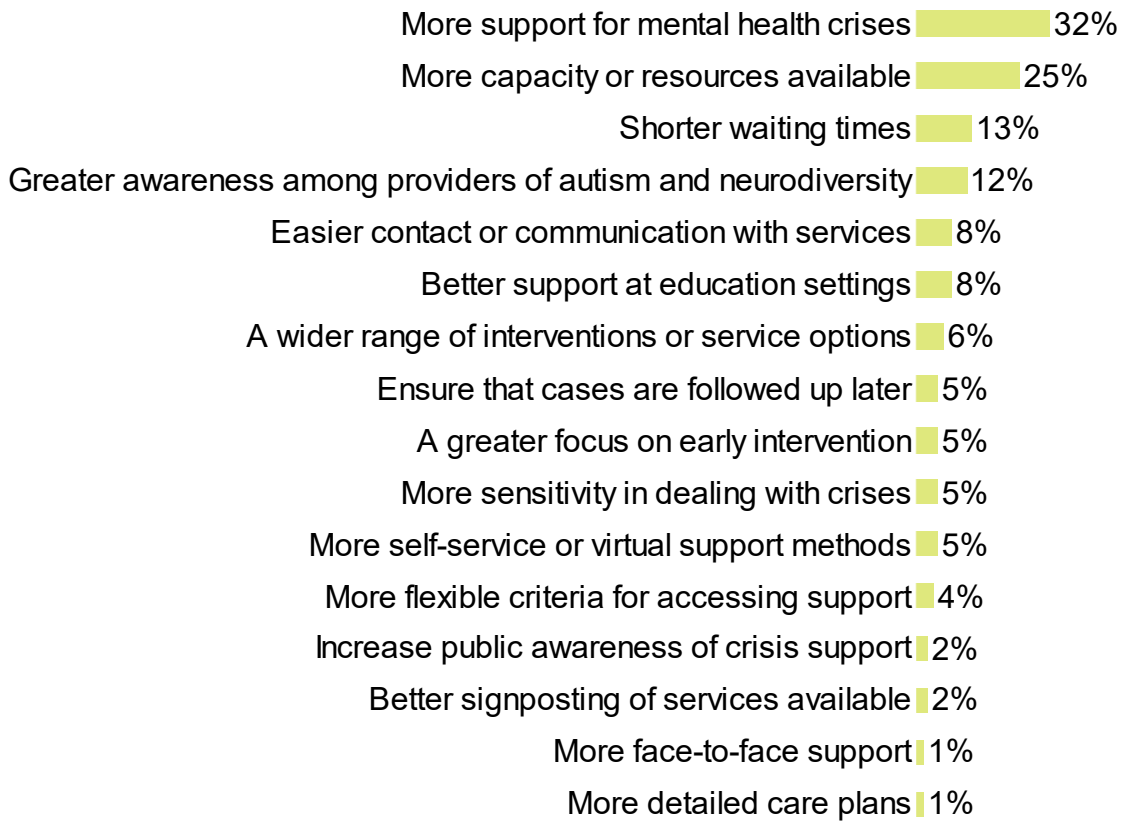
# Getting support to help autistic people in a crisis – Issues identified in all areas, with suggestions for improvements focused most on mental health support and ensuring adequately resourced services

Of the 121 respondents who had sought help for an autistic person in a crisis...

## Thinking about this crisis support...



## How could this crisis support have been improved? (Multi-code, base: 84, analysed using an automated text coding process)

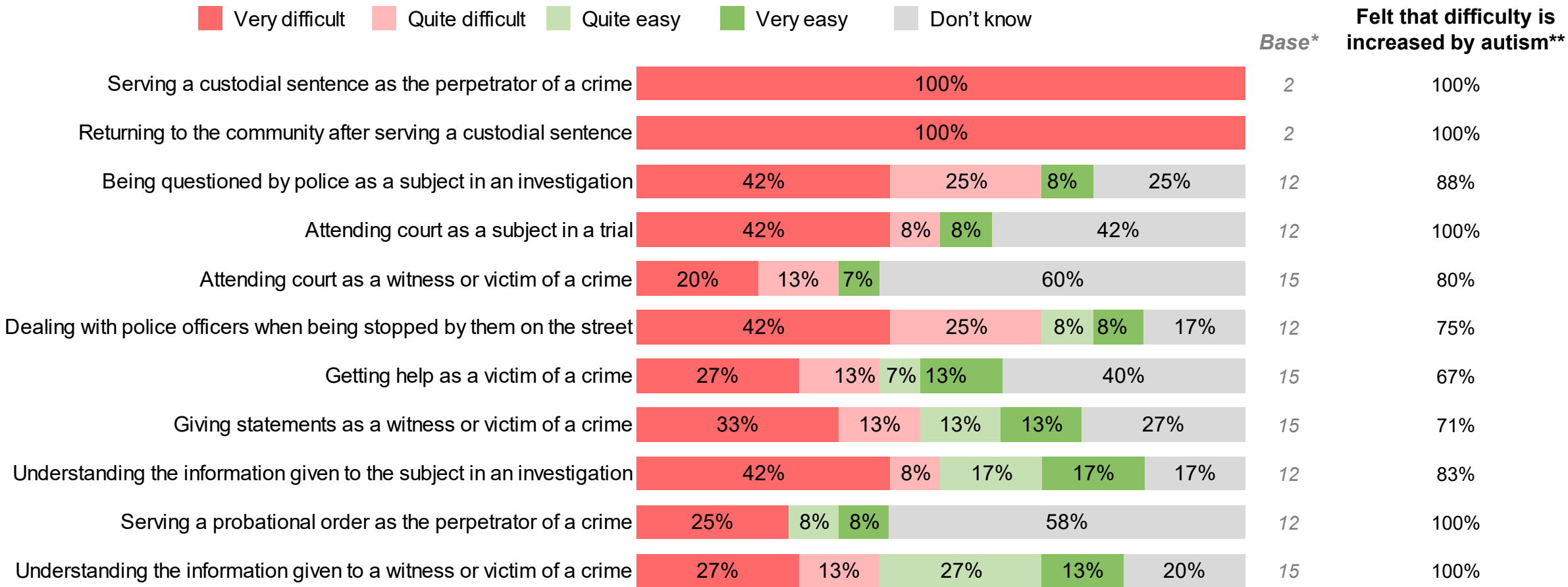


## **Priority 6**

**Improving support within the criminal and youth justice systems**

**Criminal justice-related activities** – Although relatively few autistic respondents had experienced activities involving the criminal justice system, there was a view amongst those who had that difficulties experienced as a result of autism were greatest for those being handled as subjects or perpetrators of offences

How easy or difficult is...(responses of autistic individuals, ranked by most difficult when ignoring 'Don't know' responses)



*\*Please note the very low base sizes for these questions*  
*\*\*Of those who responded that this activity is very or quite difficult*



# Suggested ways to help autistic people when engaged with Criminal Justice Services

What changes could help autistic people when engaged with Criminal Justice Services?  
(Multi-code, base: 77, analysed using an automated text coding process)



More than half of comments suggested that there should be **training for front-line officers**, with whom autistic people are likely to engage in public, to work with and support autistic people.

In addition, one fifth of replies suggested that there should be **training for support staff** who assist autistic people when they are engaging with criminal justice services.

A similar proportion suggested that the **information** provided to autistic people should be clear, simple, or carefully explained to ensure that it is understood.

Respondents also mentioned that autistic people should have access to an **advocate** to help them to have their needs and views understood and represented to criminal justice services.

Concerns about **mental health** impacts for autistic people were also mentioned, with feelings that there should be an awareness of the impacts of engaging with criminal justice services and that there should be adequate support from these services to support autistic people.

There were also suggestions that criminal justice services be mindful of the **time requirements** for adequately supporting autistic people, and to ensure that timings and expectations are arranged to ensure that autistic people are not rushed in their interactions with these services.

# Suggested ways to help autistic people when engaged with Criminal Justice Services – examples of comments

## Training for front-line officers

*“As an ex police officer there is little to no education around autism, or neurodiversity such as ADHD which means people are more likely to come into contact with the criminal justice services”*

*“all officers to be properly trained in the needs of the autistic and to understand they are there to serve us”*

*“...police need to have better training in dealing with people with autism or MH issues in general”*

## Training for support staff

*“A support person, who knows the law and who is trained in working with autistic individuals to support and assist them in understanding what is being said and what is expected from them”*

*“...an expert in autism at any hearing to explain to the judge / jury from the autistic point of view”*

*“Training for staff to recognise signs of possible autism/additional needs”*

## Providing clear information to autistic people

*“Language assessments to help criminal justice services understand the comprehension and expression needs of those they are working with”*

*“Use of visuals and breaking down information into small steps to aid understanding”*

*“Consideration that they might need interviews / communication to be discussed in a different way than is the 'standard'”*

*“An appropriate non stressful environment and use of the right communication methods”*

## An advocacy service

*“Ensure any law enforcement service is aware of your condition and an advocate or legal representative is present during any meetings”*

*“The criminal justice system is very complex particularly for people with autism. a fully autism trained advocate would be most helpful”*

*“Having an up to date assessment...and access to advocate services, to ensure they understand the process”*

## Awareness of mental health impacts

*“...it is important to understand that an autistic person can easily become violent as a reaction to stress/anxiety but when that anxiety subsides there can be a lot of remorse. It's all about understanding the cause of the behaviour because in isolation the behaviour can be really bad”*

*“...someone in place to deal with mental health issues”*

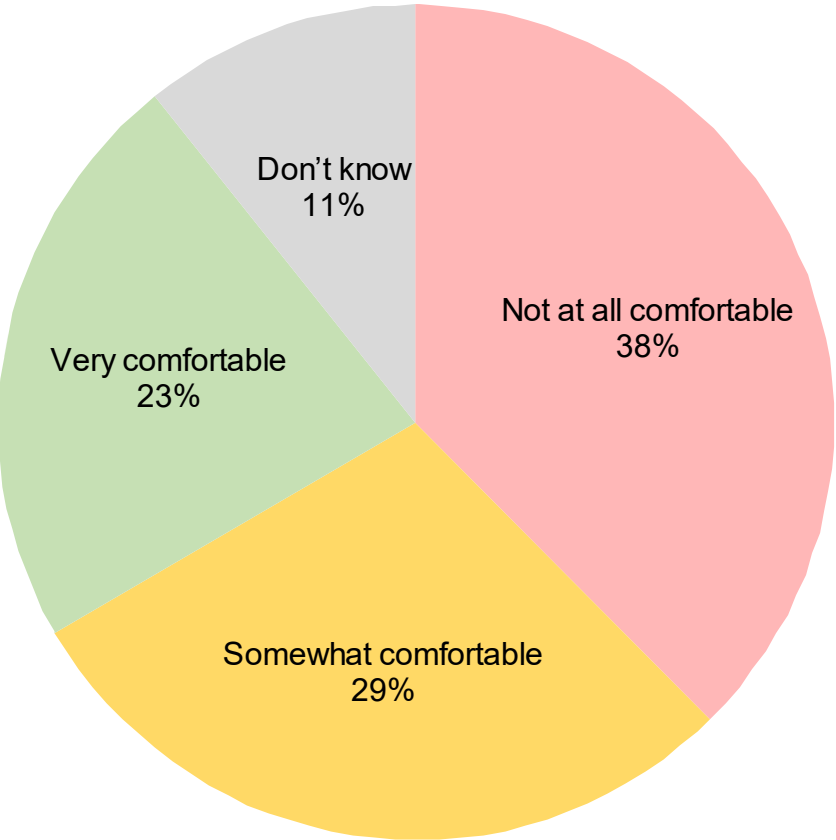
## Provide necessary time to support autistic people

*“Allow an autistic person to pre-record their evidence and answers to questions. This should allow them to process the information in their own time and be less stressed so produce more coherent answers”*

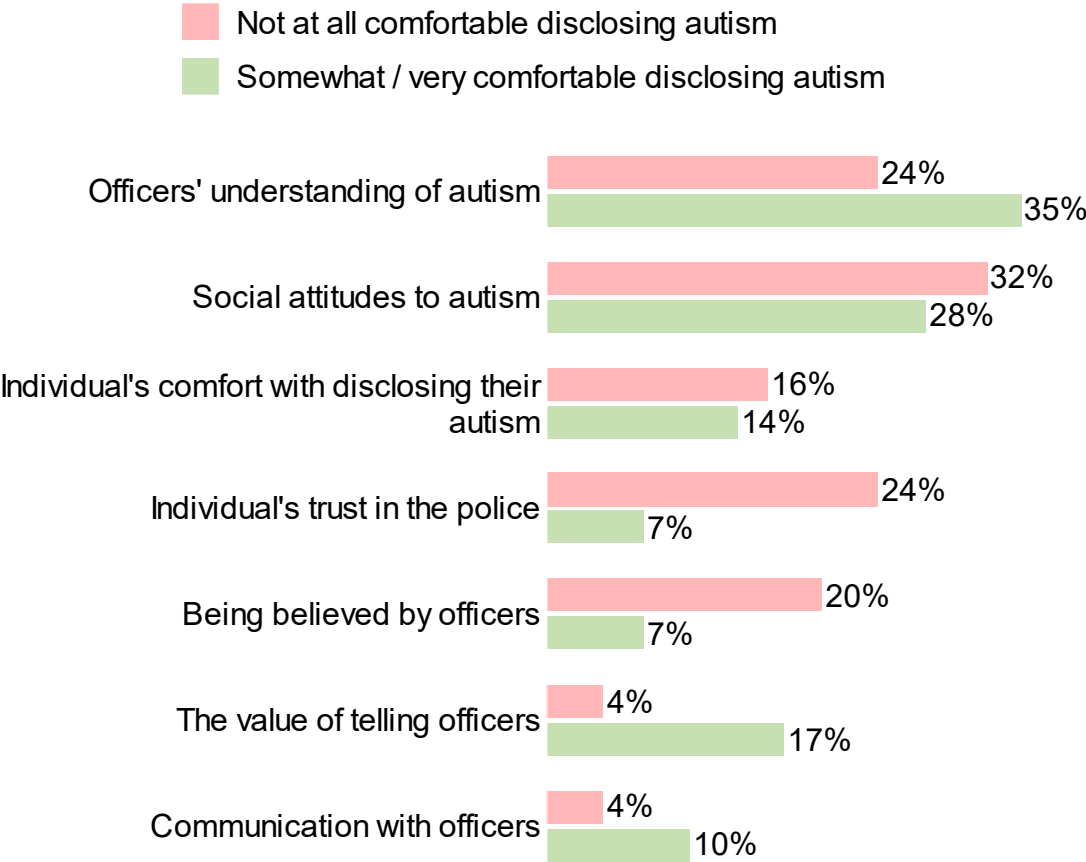
*“When stressed, autistic people take more time to process information and to respond. Others should be calm, patient and clear in what they say”*

# Disclosing autism when dealing with a police officer – Those uncomfortable to do so most frequently mentioned social attitudes to autism, as well as a lack of trust in the police and their understanding of autism

How confident would you be in disclosing your autism to a police officer? (Responses from autistic respondents, excludes 'Not applicable' responses, base: 93)



If you are autistic, please explain why you answered in this way (Multi-code, base: 54, analysed using an automated text coding process)



# Meeting autism-related needs when engaging with criminal justice services

## Autistic peoples' needs as witnesses or victims of crimes

16 of the 37 autistic respondents who had experienced this situation felt that their needs were met 'poorly' or 'very poorly'

Needs that were described as not being met included:

- support helping autistic people to understand the information they were given, such as with plain English or with visual aids;
- awareness of disabilities, and the limitations these can place on people;
- sensitivity when dealing with autistic people, such as maintaining a calm environment and non-threatening manner; and
- access to other services to support diverse people, such as ethnic minorities, LGBT individuals, and those with disabilities.

## Autistic peoples' needs as subjects of crimes

17 of the 33 autistic respondents who had experienced this situation felt that their needs were met 'poorly' or 'very poorly'

Needs that were described as not being met included:

- sufficient police resources (manpower, time) to support the individual;
- the presence of legal representation that was familiar with supporting autistic people;
- transport assistance when attending court;
- support to help the individual to understand what they were being told or asked; and
- awareness of the symptoms of autism by investigating officers.

## Autistic peoples' needs when serving custodial sentences for crimes

All 5 of the autistic respondents who had experienced this situation felt that their needs were met 'poorly' or 'very poorly'

Needs that were described as not being met included:

- consideration of autism when issuing a sentence;
- commitment to supporting autistic people during their sentence; and
- helping autistic people to understand what they are told and helping them to communicate with the criminal justice services.

# Suggested ways to help autistic people when being supported as witnesses or victims of crimes

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## **Improving service providers' awareness of the needs of autistic people**

*"Knowledge that although impression given [is] that [the] victim is ok - actually the emotional impact is considerable - give us extra time to process new information"*

*"Training police better to understand autistic traits and see beyond stereotypes"*

*"Greater awareness of how autistic people express distress and how it can be alleviated"*

## **Addressing the communication needs of autistic people**

*"[Ensure that autistic people are] forewarning of the process"*

*"Use of visual cues"*

*"Give us extra time to process new information"*

*"One phone call to individual to explain outcome totally inadequate - left with no understanding of the outcome even though [individual] stated they did"*

## **Ensuring access to support for autistic people and their carers**

*"A support worker"*

*"Ensuring all key stakeholders are involved in the process"*

*"Access to support [by people] who are sufficiently trained"*

*"Tailored support at every stage. Making the support that is meant to be there actually available"*

*"Adequate trauma aware education and care to help them regulate their nervous system after stressful incidents"*

*"[My] anxiety went through the roof despite nice police officers, backed out prior to court as so worried"*

# Suggested ways to help autistic people when being supported as potential subjects of crimes

## Support for autistic people with navigating criminal justice processes

*"[Criminal Justice Services] need to be trained and told that autism isn't identifiable through looks"*

*"Having someone with experience of dealing with autistic people present in the interviews etc"*

*"My son definitely needed a parent or another person with them who knows them to help them understand what is going on - even though the police were very good at repeating the questions etc... asking them in a different way helped. it is a stressful environment so clear thinking... goes out the window"*

*"Only 1 to 1, not 3 people"*

*"Being able to access a registered intermediary (who has been trained in autism and neurodivergent-affirming practice)"*

*"The process is far too stressful even for a minor offence"*

*"Training in autism awareness for police, court officials etc. specific procedures put in place to follow when dealing with an autistic person to make sure the right support is accessed at the earliest opportunity"*

*"Advocates who can be assigned to support individuals throughout the whole process"*

## Clear communication that autistic people can understand

*"Awareness of autism related communication difficulties"*

*"[Autistic people and those who care for them] should be made aware of their rights should they be involved with the police"*

*"An understanding of how best to communicate to a person with autism. clear, literal language and an understanding of the importance of non verbal communication, including tone of voice"*

*"Less eye contact"*

*"Professionals trained in communication and how to make this accessible to those with communication needs"*

## Support to prevent further offences being committed

*"Advice and support to help reintegrate back into community"*

*"Support to help prevent autistic/adhd people becoming addicted to substances / crime, or specific relapse prevention support"*

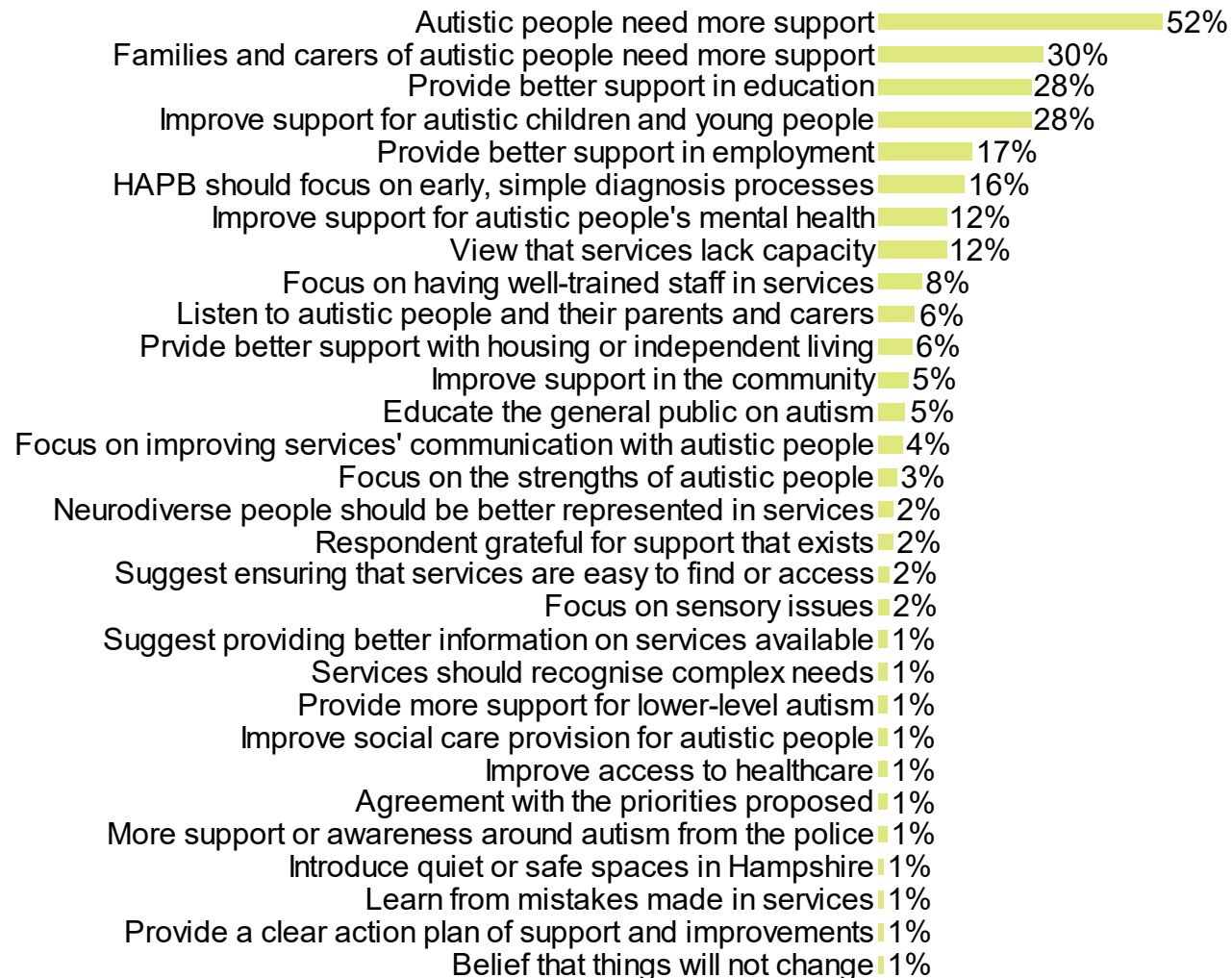
*"Support for young people over 18 should be given when they are breaking the law. The majority of the time, there's an underlying reason they've taken that route and police and prosecutors should try to find out what's going on with a young person rather than just prosecute them"*

*"It doesn't feel right that Youth Offending Team team only support up to 16, i feel they should support beyond that, maybe to 21 or 25"*

**Further comments and suggestions**

## Further comments and suggestions

Is there anything else that you would like to tell us, which is relevant to the priorities listed, that you have not had the chance to? (Multi-code, base: 173, analysed using an automated text coding process)



Just over half of responses indicated a need for greater **support for autistic people**, with just under a third mentioning that support was needed for **families and carers** of autistic people.

Where more specific ways to provide support were mentioned, these most commonly related to:

- **education**, such as by improving staff skills, capacity of specialist support, and making reasonable adjustments to ensure that autistic students have opportunities at school;
- focusing on **supporting children and young people**, at pre-school ages and throughout their childhood, to give them the skills to lead independent, productive lives;
- helping autistic people in **employment**, both when searching and applying for work, and also to help them function in the workplace when they have jobs;
- the autism **diagnosis process**, which when mentioned was frequently described as hard to access, slow, and complex to navigate;
- concerns about the **mental health** of autistic people, and those who care for them, which can suffer; and
- observations that services that support autistic people lack **capacity** to deliver the support that is needed.



## Further comments and suggestions – examples of comments

### Support for autistic people

*“Grown ups as well as children need better facilities, more acknowledgement of how difficult life can be when you are perceived as ‘not quite normal’. better general understanding of autism would certainly help”*

*“Until my son was diagnosed, I’d no idea just how much being autistic makes every single aspect of life harder”*

### Support for families and carers

*“Please could more understanding...of the difficulties of parents/carers of autistic people be given. Support groups/advice and trained experts in this field would be a great help for struggling families”*

*“...more easy access to support for parents/carers to help them understand about autism and how to bring up and support an autistic child”*

### Support in education

*“It needs to be made a priority...in education to understand and allow acceptance and reasonable adjustments”*

*“Start with educational support. If they feel supported they will gain more confidence and this will make life easier for them”*

*“We struggled in senior school, and college getting called in regularly with the question - is your son alright?”*

### Support for children and young people

*“More support and services for preschool age children 0-4...More send resource places or specialised nurseries are needed”*

*“All children and young people with autism should have direct support from specialist services, including educational psychology, speech and language and occupational therapy”*

### Support for employment

*“...there should be financial support direct to employers for hiring autistic people as that would enable employers to provide additional support in the workplace”*

*“More needs to be done to support neurodivergent individuals in getting into work and making the big transition from a structured school regime and into the work place”*

### Improving the diagnosis process

*“The EHCP process is dreadful. It took years to navigate it, not the 20 weeks it should be”*

*“From listening to friends who have younger children with autism there still needs to be extra support and speed around EHCPs, referral for diagnosis, the wait time for diagnosis and access to extra support”*

### Support for mental health

*“We are on our knees. My husband and i now both take anti-depressants”*

*“I’m hopeful by submitting all of this information i can help myself and other autistic people who suffer loneliness and depression due to lack of success in socialising with others and others who want relationships but any effort to do so never gets off the ground”*

### Issues with service capacity

*“We have had a sharp decline in the number of carers, direct support workers and services who can provide support for children/young people/adults and their families”*

*“...there’s not enough resources for the number of people we have that need additional support”*

## **Appendix: Methodology and Respondent Profile**

# Methodology

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The survey was open from 5 August 2022 until 09 October 2022. It was an open survey, so respondents were self-selecting. Most questions were optional, and were only mandatory to allow the County Council to understand some basic information about whether the respondent was responding as an individual, as an organisation, or in the capacity of a democratically elected representative.

An online survey was provided through which respondents could respond as an individual, or in an official capacity on behalf of an organisation, business or group, or in their capacity as a democratically elected representative.

The survey form was available in printed format on request.

An easy read version of the survey was available online and in print on request.

The survey was communicated through a range of channels, including:

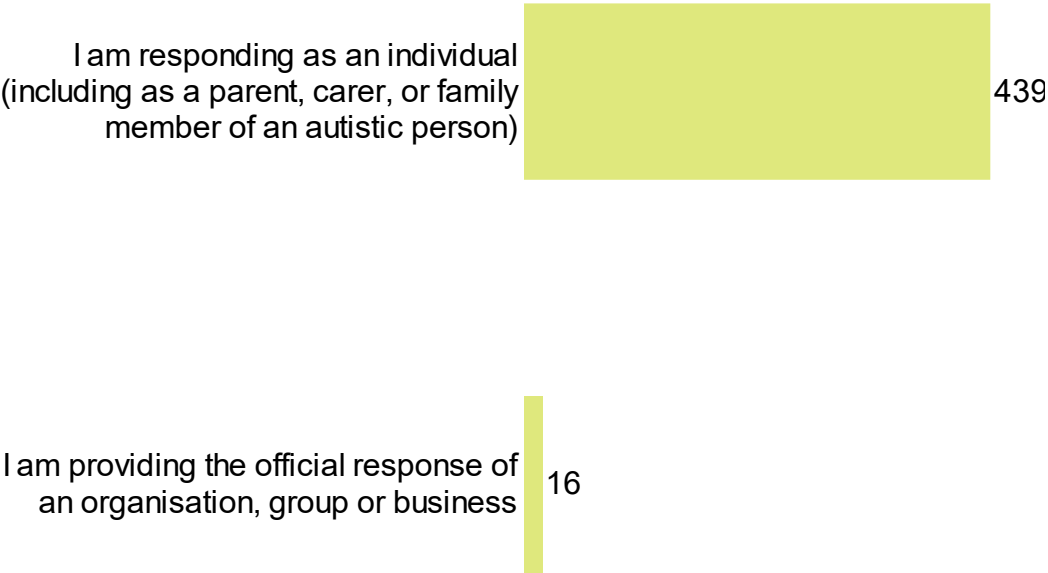
- emails and messages to stakeholders, including service users, other local authorities in Hampshire, and organisations which work with autistic people;

- social media posts; and

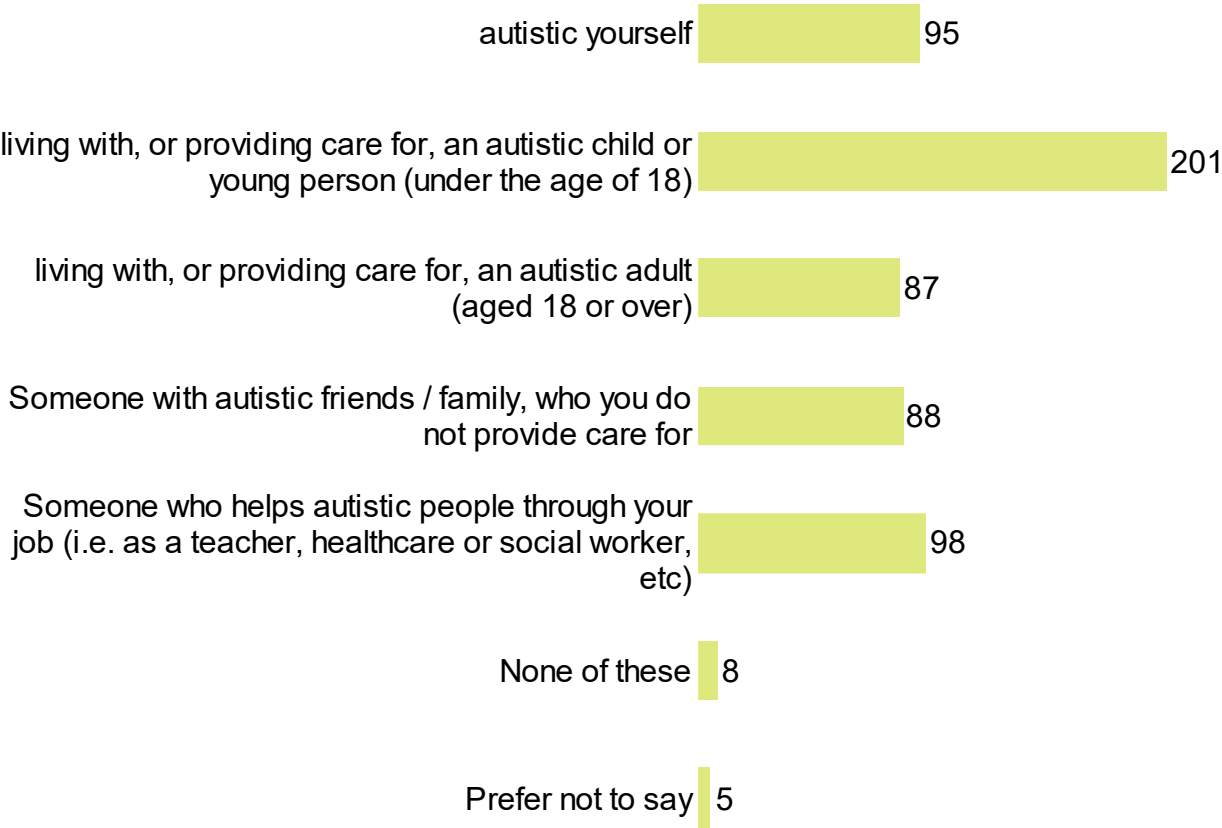
- internal communications at Hampshire County Council.

# Who responded?

On what basis are you responding to this survey? (Base: 455)



Are you... (Multi-code, base: 439)



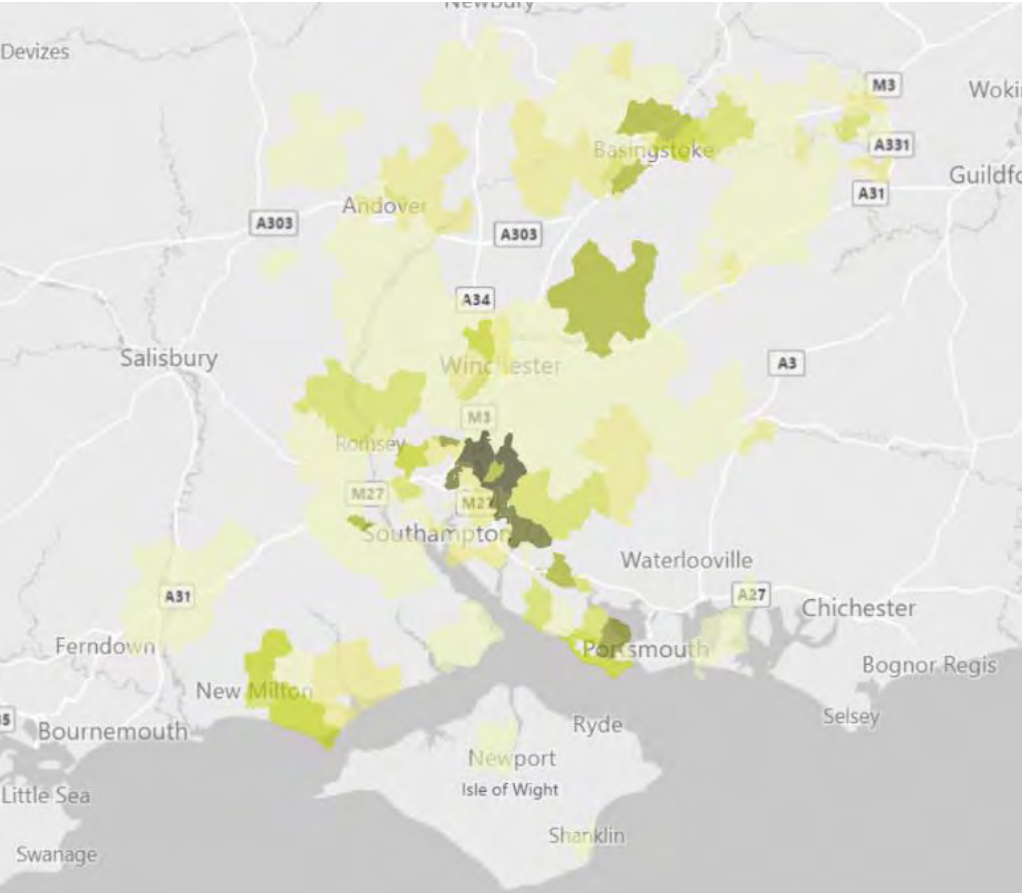
# Who responded? *Details of the organisations, groups and businesses that responded*

Names of the organisations, groups and businesses that responded	Which of these best describes the function of your organisation, group or business? (Base: 16)
<ul style="list-style-type: none"><li>Candover Valley Pre-School</li><li>Colden Common Primary School</li><li>Fledge Supported Housing</li><li>Hampshire and Isle of Wight Educational Psychology Service</li><li>High Mead Community Therapy Farm CIC</li><li>Horns Drove Community Pre-School and RASCALS</li><li>North West Mental Health Team (Hampshire County Council)</li><li>Prospect School</li><li>SAY Group</li><li>SEND Leaders at Gosport and Fareham Multi-Academy Trust</li><li>Southern Health</li><li>SpudTech.Shop</li><li>St John the Baptist Primary School</li><li>St Mary's Bentworth Church of England Primary School</li><li>The Aviary Nursery</li><li>Youth Offending Team (Hampshire County Council)</li></ul>	<div><div>Charity, voluntary or local community group</div><div></div><div>4</div></div> <div><div>Local business or business representative (e.g. BID)</div><div></div><div>1</div></div> <div><div>Local authority (e.g. county, district, parish, town or borough council)</div><div></div><div>2</div></div> <div><div>Nursery, school, college or place of education</div><div></div><div>7</div></div> <div><div>Other public sector organisation (e.g. Police, Fire, Health Authority)</div><div></div><div>2</div></div>

Insight. Marketing. Communications.

Who responded? Details of locations and household incomes of the 439 responses submitted by individuals

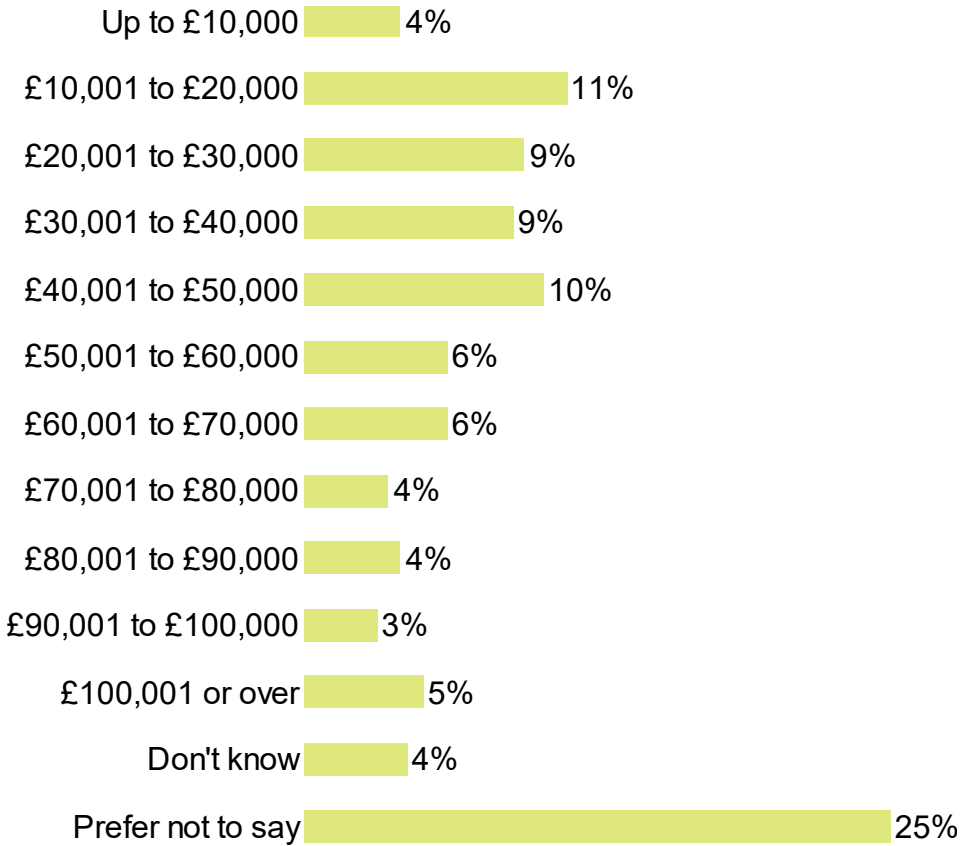
Responses by postcode district



1 response

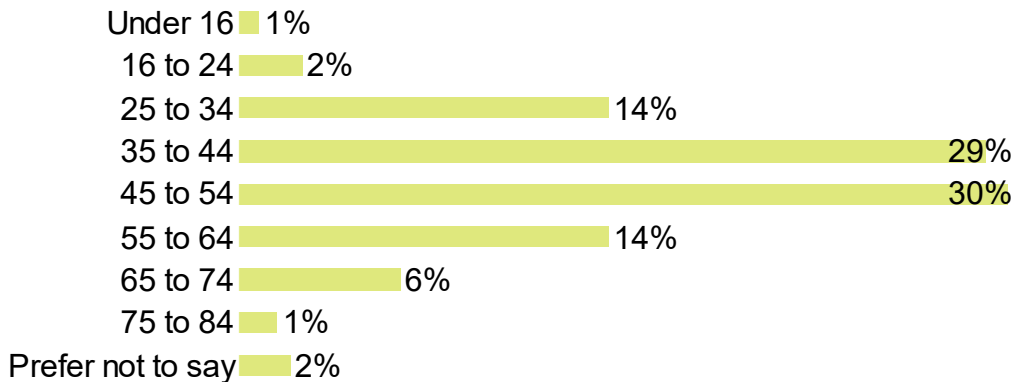
8 responses

What is your total annual household income, from all sources, before tax and other deductions? (Base: 398)

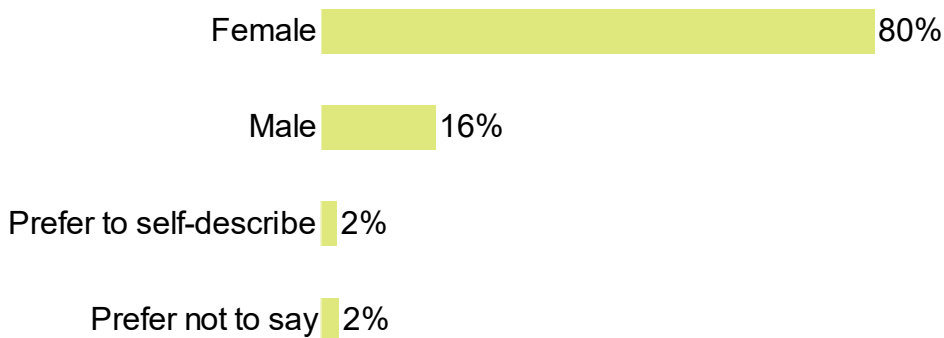


# Who responded? *Details of the 439 responses submitted by individuals*

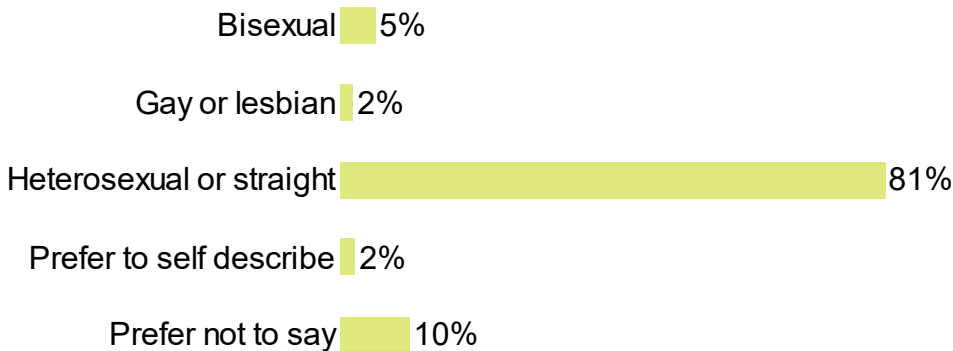
What is your age? (Base: 420)



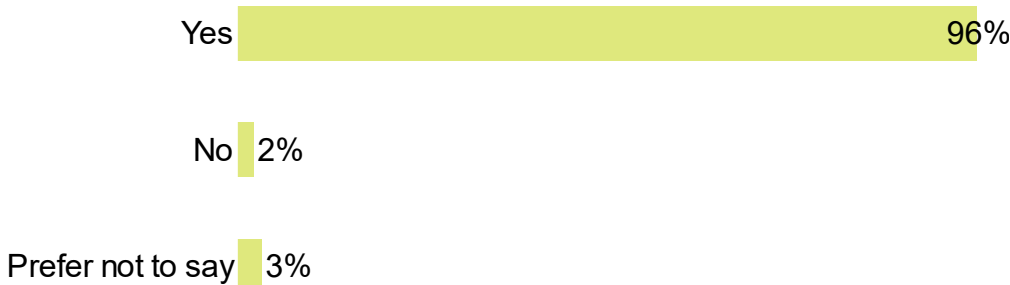
What is your gender? (Base: 417)



What is your sexual orientation? (Base: 410)

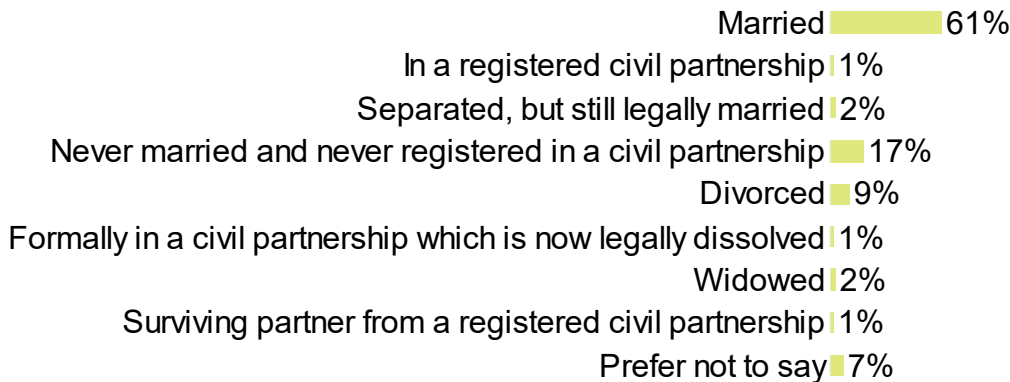


Is the gender you identify with the same as your sex registered at birth? (Base: 412)

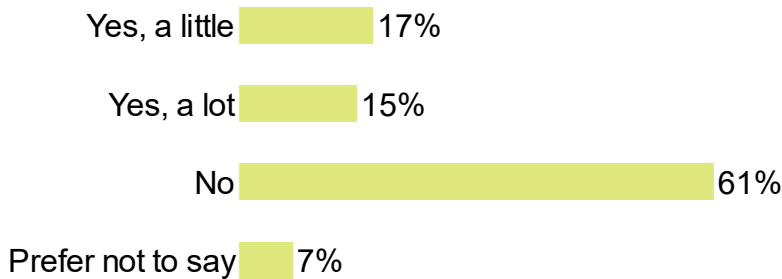


# Who responded? *Details of the 439 responses submitted by individuals*

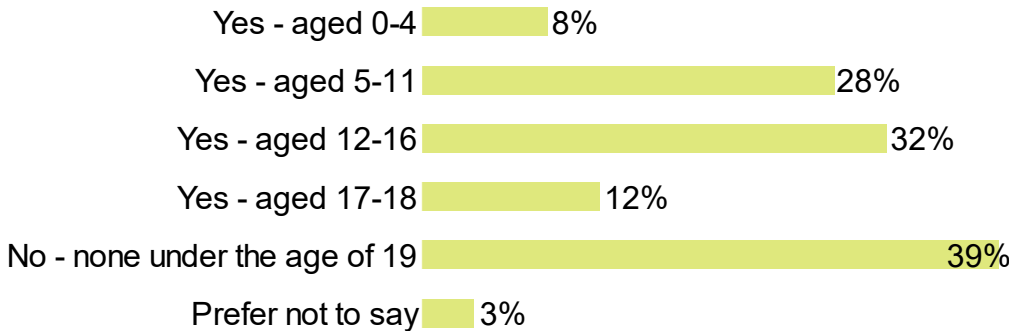
## What is your current relationship status? (Base: 415)



## Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months? (Base: 418)



## Are there any children or young people under the age of 19 living in your household (including yourself)? (Multi-code, base: 416)



## Ethnicity (Base: 290)

