

A knowledge exchange project to explore what autistic adults want from support after diagnosis

Lead researcher: Susanna Crowson

Principal Investigator: Dr Megan Freeth; Co-Investigator: Dr Daniel Poole

What was the research project?

Over the past six months, we have run workshops and collected questionnaire feedback from autistic adults. Participants were asked about the support they received after being given their autism diagnosis. They were also asked about the support they would have liked to receive. We did this to find out what the autistic community wants from support after getting an autism diagnosis.

Who conducted the research?

Dr Megan Freeth, Dr Daniel Poole and Suzy Crowson led the research at the University of Sheffield. Together they do research with and for autistic people.

Who funded the research?

Funding for this project came from the Higher Education Innovation Fund. This fund supports research projects that share knowledge and ideas between researchers and experts by experience.

What do we already know?

More people now understand autism, but many autistic people only get an autism diagnosis as an adult. This means they often do not get the support they need early in life. There are over 1 million autistic adults in the UK. Giving the right support to people is hugely important. Research evidence shows that when people receive good support they are much more likely to have happy, healthy and long lives.

What did we do?

Our research involved 43 people who received a diagnosis on the autism spectrum as an adult. They all took part in questionnaires and some also joined workshops. In the workshops, participants were asked what type of support services should offer.

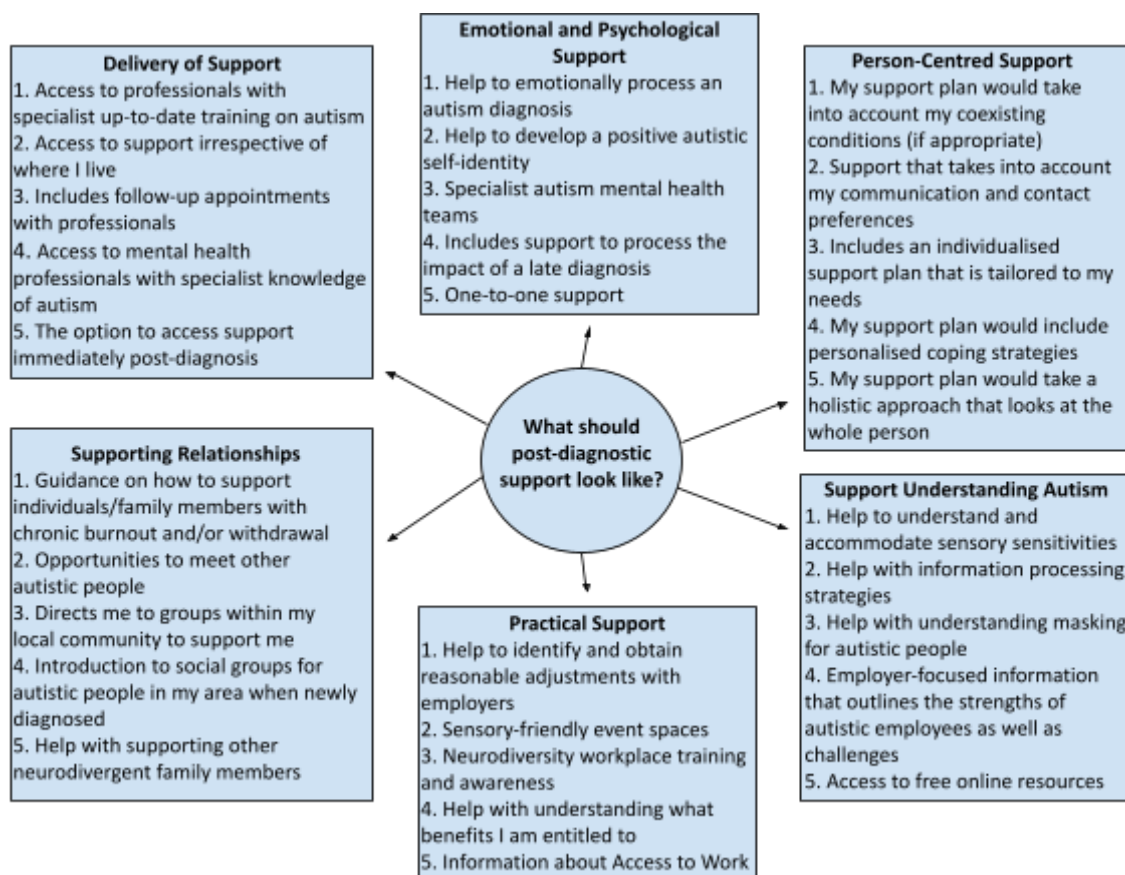
Many different people took part in the study, including autistic people from black, Asian and minority ethnic groups, the LGBTQ+ community and over 55 years of age. 28 of the 43 autistic people taking part also reported having a physical and/or mental health condition.

What were the key findings?

Autistic adults told us what they want to be included in their support - we had a total of 153 suggestions generated.

The participants told us which of the suggestions in each topic were most important to them. The boxes below show the top five most important suggestions for each topic.

A more detailed description of the entire set of items is included at the end of this report.



What happens now?

We are currently writing the findings up in a scientific paper.

We are planning to do more research on the things that matter most to autistic adults following a diagnosis. We have applied for funding for a research project that will explore more closely a personalised approach to support that is tailored to a person's strengths and support needs.

What if I have a question?

If you have any questions about this study you can email Suzy at s.crowson@sheffield.ac.uk

You can talk to us about it over the phone by calling: +44 114 222 6652

A big thank you to all our participants.

More detailed description of results

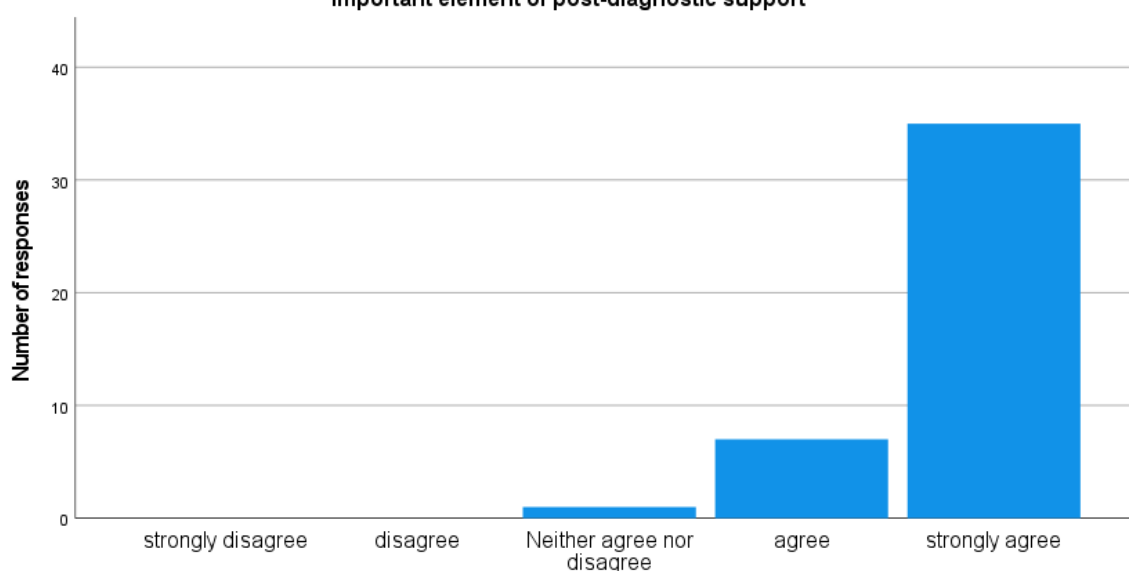
What did we find?

Here is a summary of all 153 items. We have presented the three top suggestions in each topic with a bar chart. The bar charts show the spread of participant responses. These are followed by a list of all the ideas in each of the different topics. For each topic, items are listed in order of importance as rated by autistic adults, starting with the items that received the most agreement.

Category 1: Delivery of Support

1. Access to professionals with specialist up-to-date training on autism

Responses to the statement: 'Access to professionals with specialist up-to-date training on autism is an important element of post-diagnostic support'

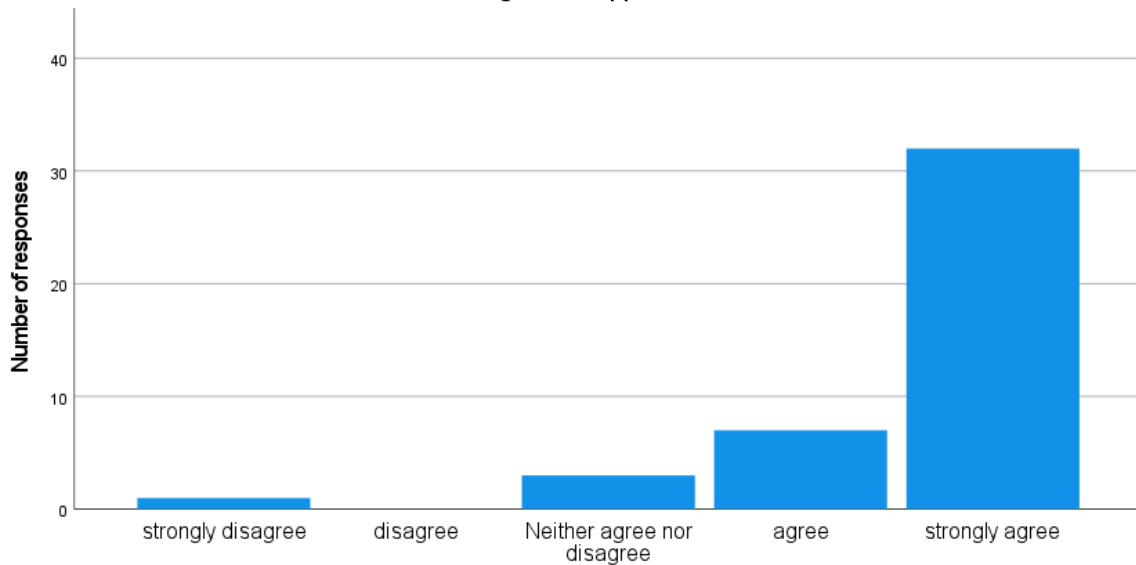


What does the bar chart tell us?

42 of the 43 participants agree or strongly agree that professionals need up to date training about autism. This will help to better support autistic people after a diagnosis.

2. Access to support irrespective of where I live

Responses to the statement: 'Access to support irrespective of where I live is an important element of post-diagnostic support'

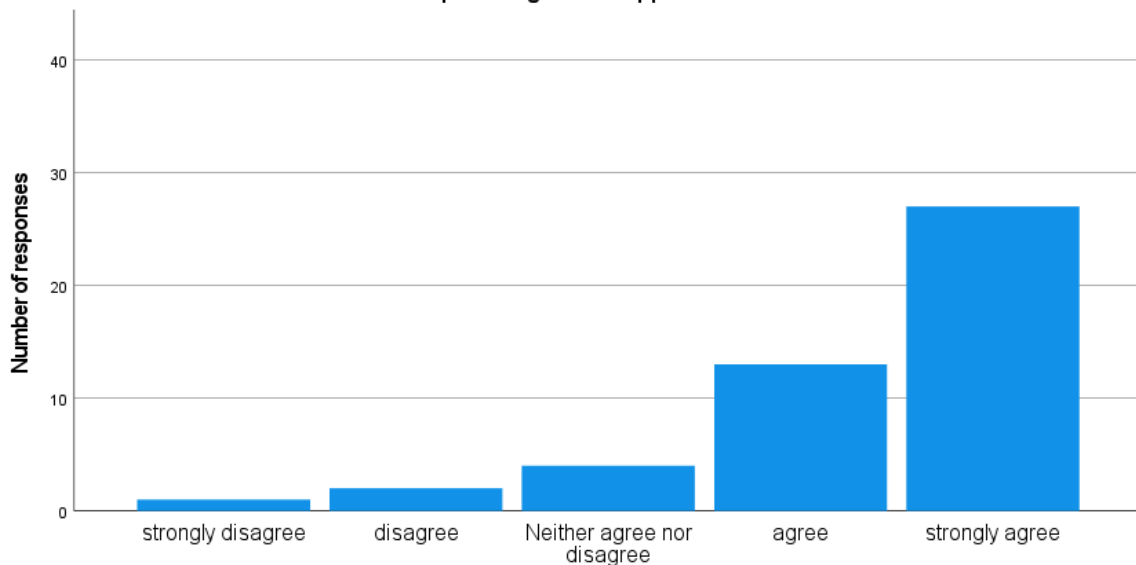


What does the bar chart tell us?

39 of the 43 participants agree or strongly agree that autistic adults should get access to the support they need wherever they live.

3. Includes follow-up appointments with professionals

Responses to the statement: 'Including follow-up appointments with professionals is an important element of post-diagnostic support'



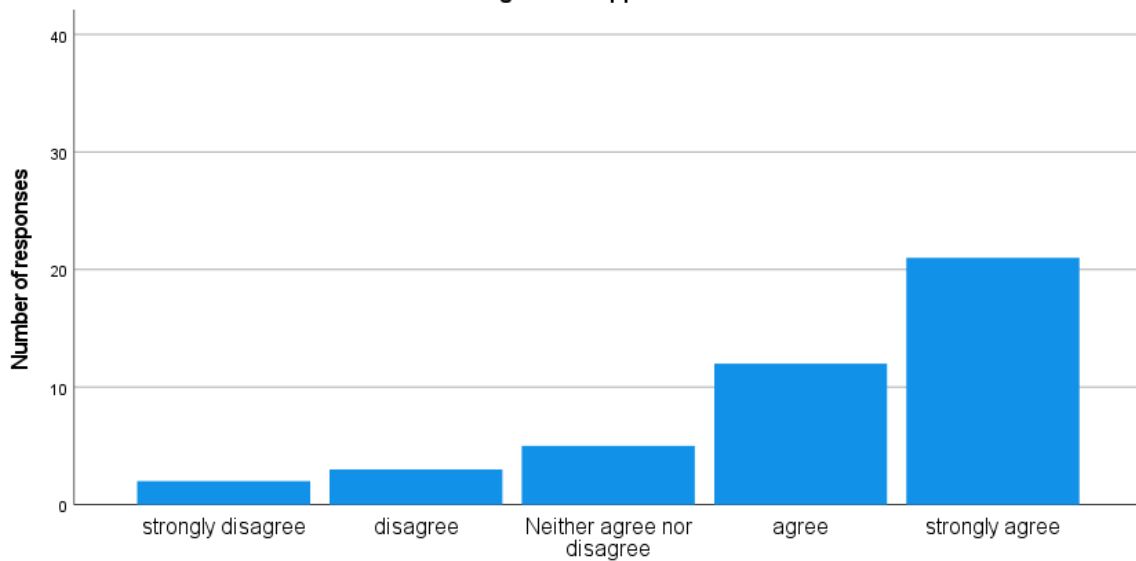
What does the bar chart tell us?

41 of the 43 participants agree or strongly agree that autistic adults should get access to follow-up appointments with professionals after being given their autism diagnosis.

Category 2: Emotional and Psychological Support

1. Help to emotionally process an autism diagnosis

Responses to the statement: 'Help to emotionally process an autism diagnosis is an important element of post-diagnostic support'

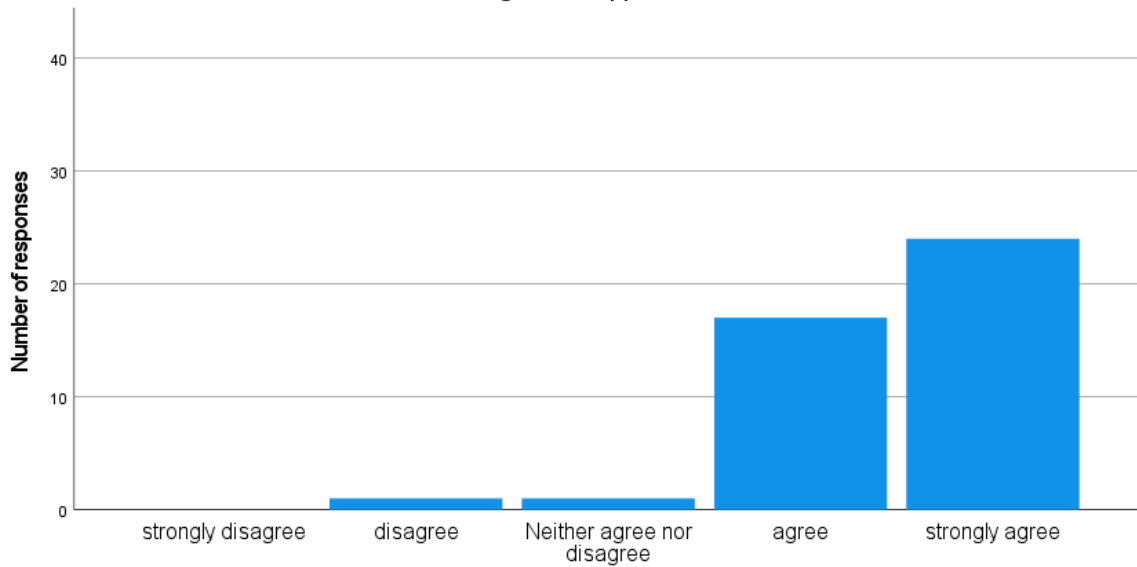


What does the bar chart tell us?

33 of the 43 participants agree or strongly agree that autistic adults should get access to support to help emotionally process their autism diagnosis.

2. Help to develop a positive autistic self-identity

Responses to the statement: 'Help to develop a positive autistic self-identity is an important element of post-diagnostic support'

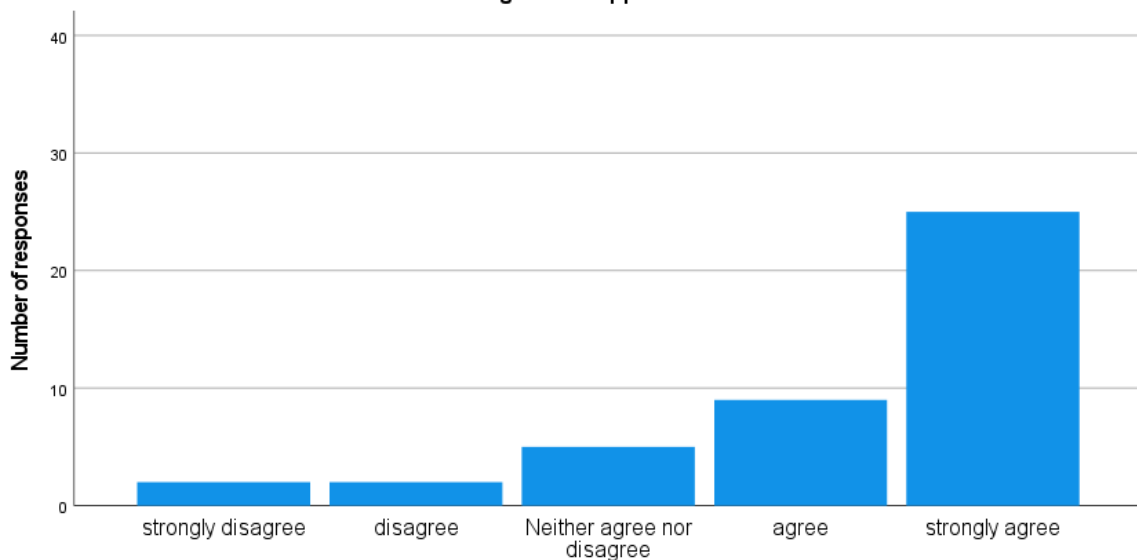


What does the bar chart tell us?

41 of the 43 participants agree or strongly agree that autistic adults should receive help to develop a positive autistic identity.

3. Specialist autism mental health teams

Responses to the statement: 'Specialist autism mental health teams are an important element of post-diagnostic support'



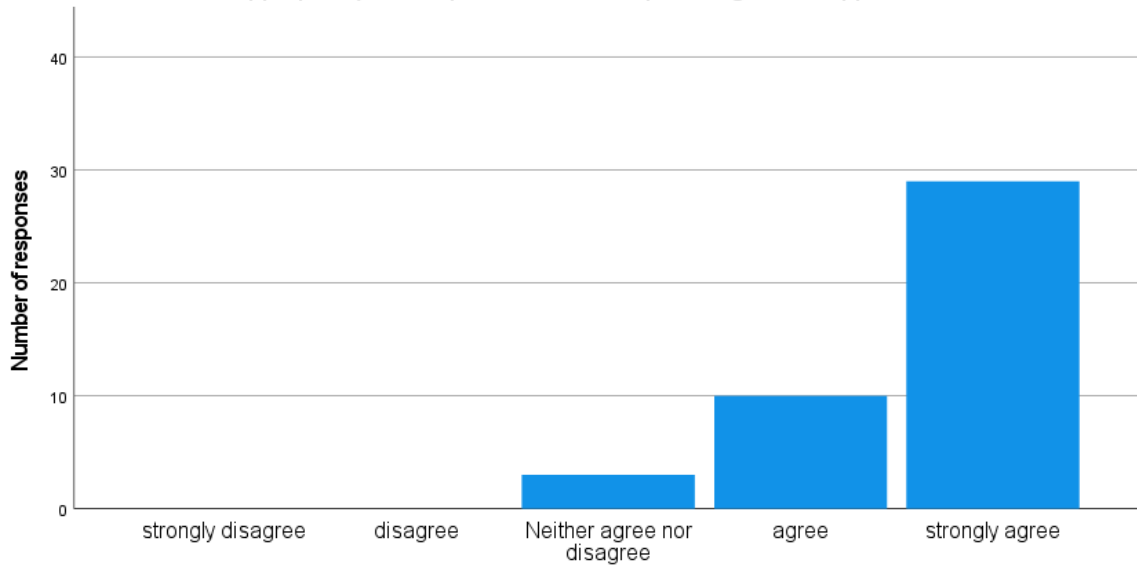
What does the bar chart tell us?

34 of the 43 participants agree or strongly agree that autism-specific mental health teams should provide support to autistic adults.

Category 3: Person-Centred Support

1. A support plan that would take into account my coexisting conditions (if appropriate)

Responses to the statement: 'A support plan that would take into account my coexisting conditions (if appropriate) is an important element of post-diagnostic support'

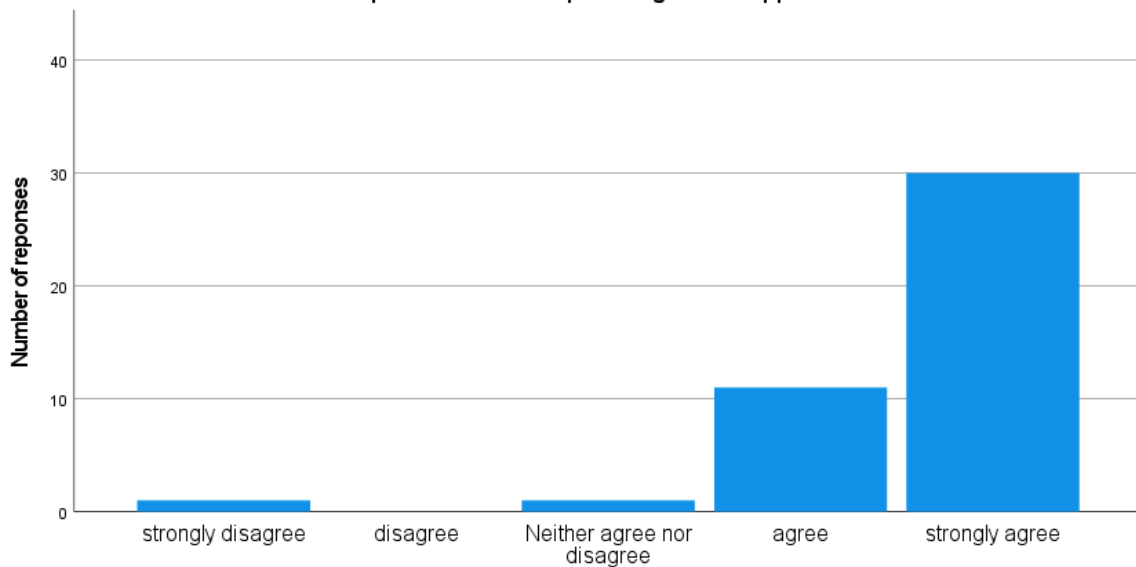


What does the bar chart tell us?

39 of the 43 participants agree or strongly agree that support for autistic adults should include a support plan that identifies and prioritises a person's coexisting conditions.

2. Support that takes into account my communication and contact preferences

Responses to the statement: 'Support that takes into account my communication and contact preferences is an important element of post-diagnostic support'

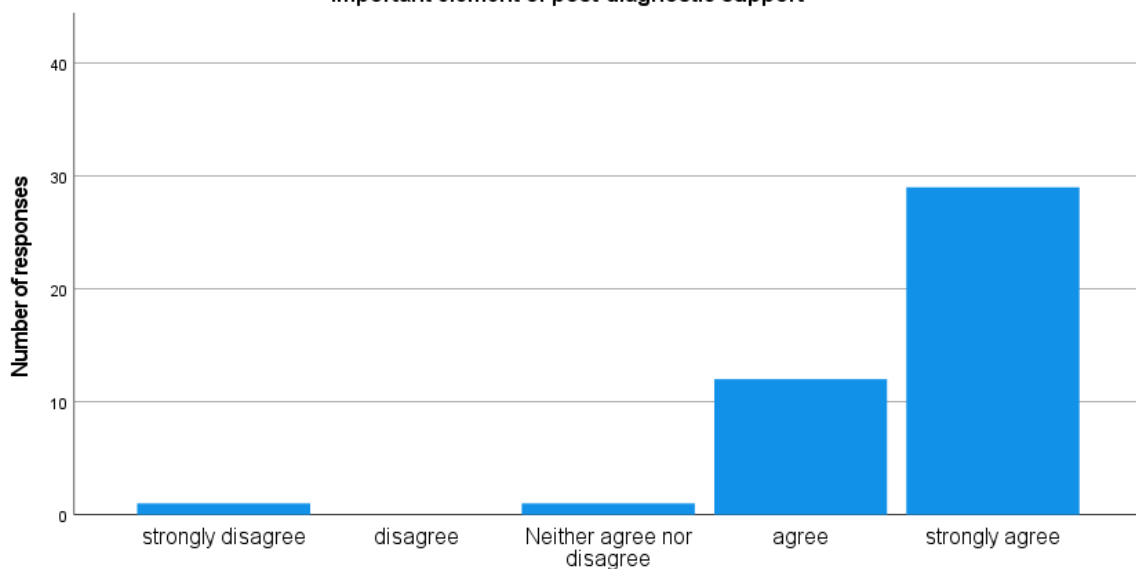


What does the bar chart tell us?

41 of the 43 participants agree or strongly agree that services for autistic adults should identify and use a person's preferred method of communication.

3. Includes an individualised support plan that is tailored to my needs

Responses to the statement: 'Including an individualised support plan that is tailored to my needs is an important element of post-diagnostic support'



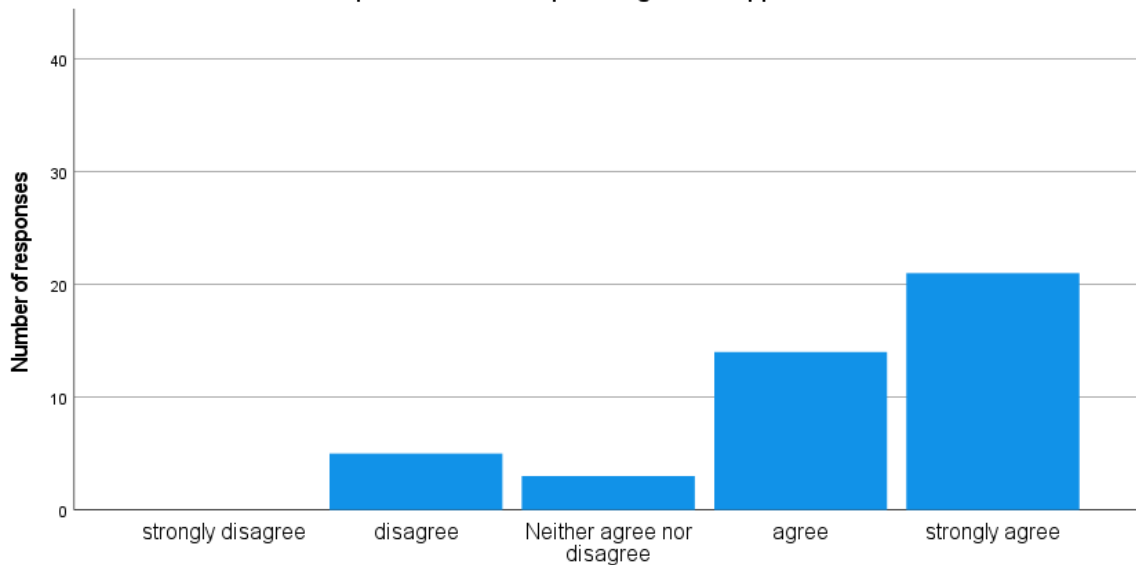
What does the bar chart tell us?

41 of the 43 participants agree or strongly agree that support for autistic adults should include an individualised support plan that is tailored to their support needs.

Category 4: Practical Support

1. Help to identify and obtain reasonable adjustments with employers

Responses to the statement: 'Help to identify and obtain reasonable adjustments with employers is an important element of post-diagnostic support'

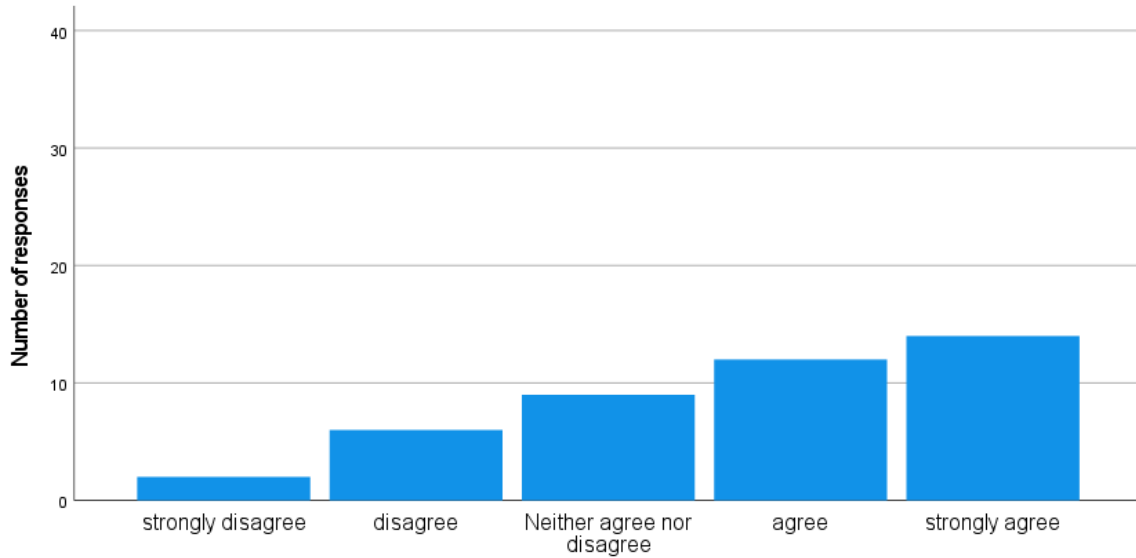


What does the bar chart tell us?

35 of the 43 participants agree or strongly agree that autistic adults should receive help in the workplace to agree reasonable adjustments with employers.

2. Sensory-friendly event spaces

Responses to the statement: 'Sensory-friendly event spaces are an important element of post-diagnostic support'

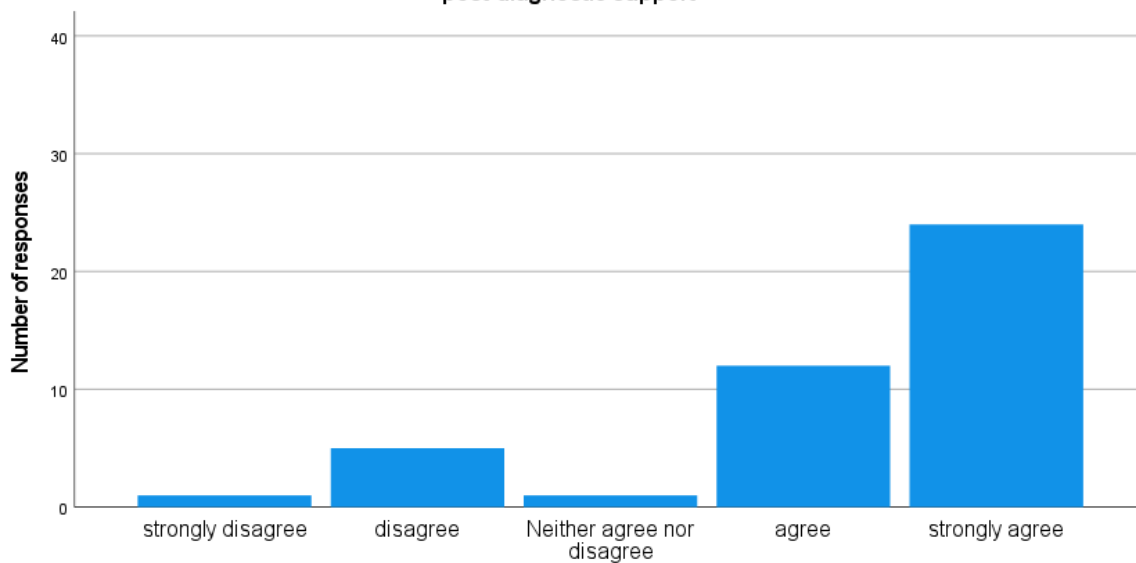


What does the bar chart tell us?

26 of the 43 participants agree or strongly agree that autistic adults should get access to event spaces that are sensory-friendly.

3. Neurodiversity workplace training and awareness

Responses to the statement: 'Neurodiversity workplace training and awareness is an important element of post-diagnostic support'



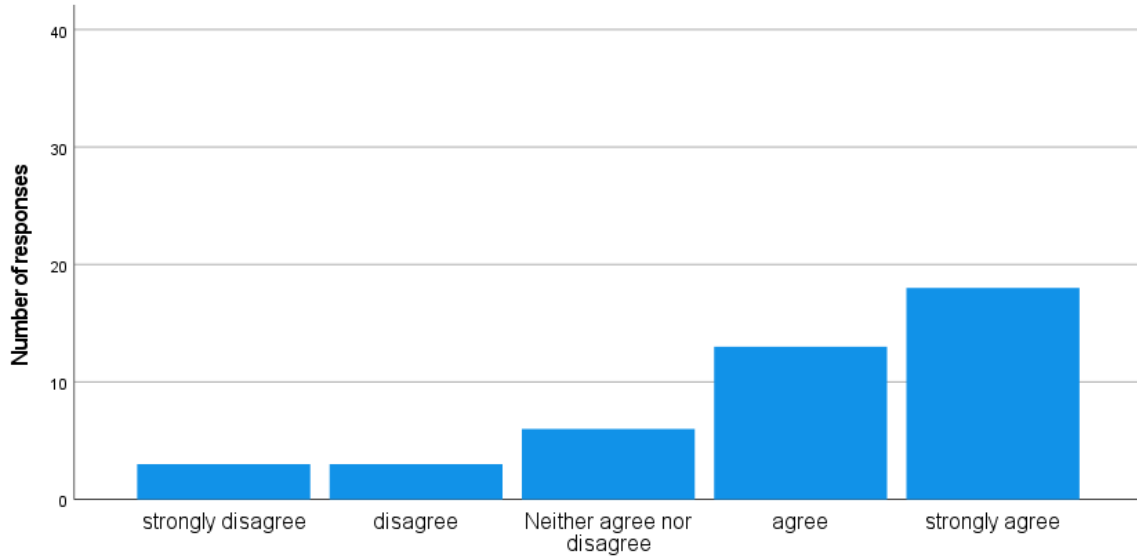
What does the bar chart tell us?

36 of the 43 participants agree or strongly agree that employees and employers need training and awareness about neurodiversity.

Category 5: Support Understanding Autism

1. Help to understand and accommodate sensory sensitivities

Responses to the statement: 'Help to understand and accommodate sensory sensitivities is an important element of post-diagnostic support'

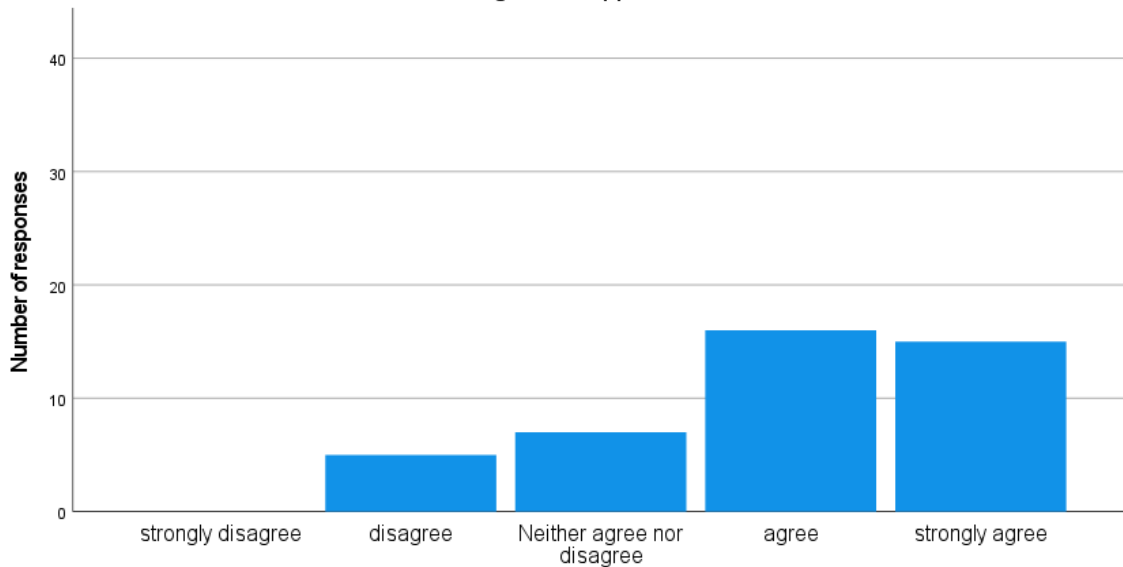


What does the bar chart tell us?

31 of the 43 participants agree or strongly agree that autistic adults should get help to understand and secure appropriate accommodations for sensory sensitivities.

2. Help with information processing strategies

Responses to the statement: 'Help with information processing strategies is an important element of post-diagnostic support'

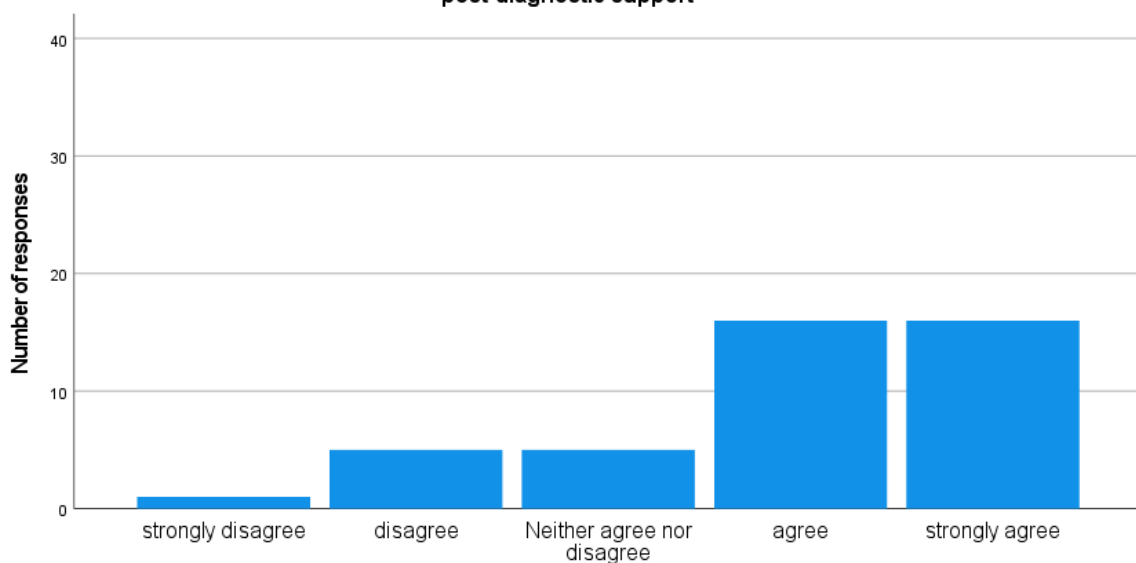


What does the bar chart tell us?

31 of the 43 participants agree or strongly agree that autistic adults should get help to understand how a person with autism might process information.

3. Help with understanding masking for autistic people

Responses to the statement: 'Help with understanding masking for autistic people is an important element of post-diagnostic support'



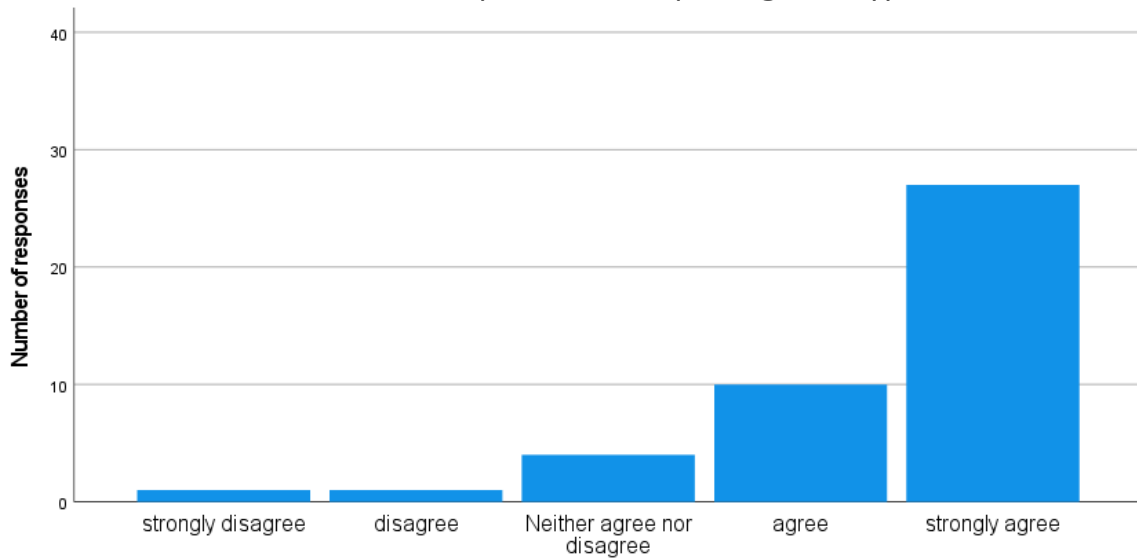
What does the bar chart tell us?

32 of the 43 participants agree or strongly agree that autistic adults should get help to understand masking in autistic people.

Category 6: Supporting Relationships

1. Guidance on how to support individuals/family members with chronic burnout and/or withdrawal

Responses to the statement: 'Guidance on how to support individuals/family members with chronic burnout and/or withdrawal is an important element of post-diagnostic support'

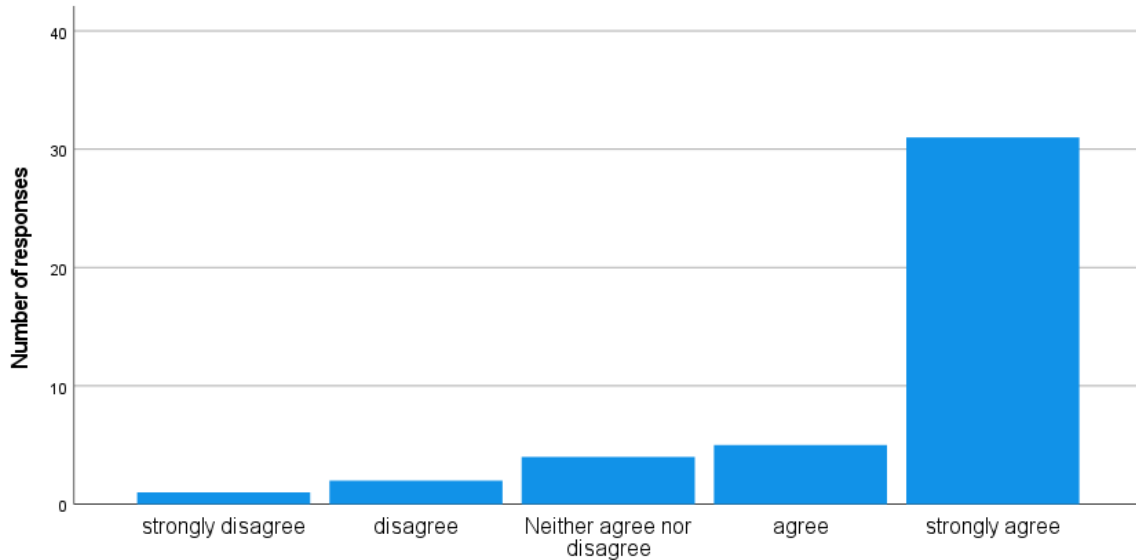


What does the bar chart tell us?

37 of the 43 participants agree or strongly agree that autistic adults should receive guidance on supporting individuals/family members with chronic burnout and/or withdrawal.

2. Opportunities to meet other autistic people

Responses to the statement: 'Opportunities to meet other autistic people are an important element of post-diagnostic support'

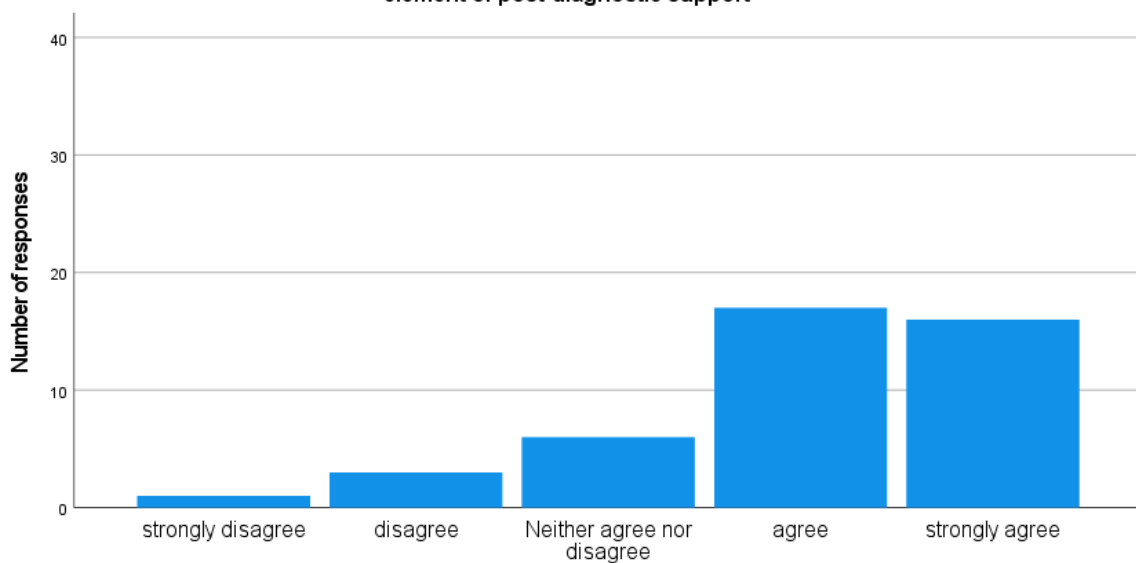


What does the bar chart tell us?

36 of the 43 participants agree or strongly agree that autistic adults should get opportunities to meet other autistic people.

3. Directs me to groups within my local community to support me

Responses to the statement: 'Direction to groups within my local community to support me is an important element of post-diagnostic support'



What does the bar chart tell us?

33 of the 43 participants agree or strongly agree that support should direct autistic adults to local groups to support them.

Here are the category 1 recommendations for delivery of support:

1. Access to professionals with specialist up-to-date training on autism
2. Access to support irrespective of where I live
3. Includes follow-up appointments with professionals
4. Access to mental health professionals with specialist knowledge of autism
5. The option to access support immediately post-diagnosis
6. Services designed in collaboration with autistic people
7. Inclusive autism-specific services
8. Access to support from the same professional(s)
9. Healthcare professionals including my GP are kept informed by other support services
10. Help accessing support with social anxiety
11. Access to support irrespective of where my autism diagnosis is from
12. Help with navigating and accessing support
13. Help disclosing my autism diagnosis to others in my personal life/workplace when I feel ready
14. Includes assessment for any co-occurring conditions
15. Access to support information designed for autistic people
16. Option to involve people close to me including a friend, family or partner
17. Services stay in regular contact with me in a way that suits me
18. Help with accessing healthcare
19. Access to autistic professionals
20. A named key worker as my central point of contact
21. Help accessing services from a single point of contact
22. Life-long support
23. Help to identify and obtain reasonable adjustments within healthcare settings
24. Services make initial contact with me in a way that suits me
25. Autism inclusive hospital passport
26. Access to resources written by autistic people
27. Help to identify and obtain reasonable adjustments within education, volunteering and training
28. Help interpreting support information designed for neurotypicals
29. Help with organisation and planning
30. Assistance going to appointments
31. Assistance arranging travel to and from groups and activities
32. Assistance going to groups and activities
33. Access to services where there is car parking on site

Here are the category 2 recommendations for emotional and psychological support:

34. Help to emotionally process an autism diagnosis
35. Help to develop a positive autistic self-identity
36. Specialist autism mental health teams
37. Includes support to process the impact of a late diagnosis
38. One-to-one support
39. Therapy and/or counselling for me
40. Help to build self-confidence
41. Help with autistic fatigue
42. Help with self-empowerment
43. Specific support with chronic burnout and withdrawal
44. Help with handling rejection
45. Help differentiating between chronic burnout and other conditions e.g. depression
46. Peer mentoring
47. Tools for self-guided help
48. Group support with other recently diagnosed adults
49. List of peer support groups for newly diagnosed autistic people
50. Help with understanding intergenerational patterns and/or trauma
51. Links to appropriate groups on social media
52. Group support with autistic people
53. Group support with other autistic people of a similar age to me
54. Groups for sharing diagnostic disclosure experiences
55. Animal assisted therapy
56. Automatic social services referral that leads to autism-friendly support
57. Information on relevant mailing lists
58. Autism assistance dogs
59. Text message based support

Here are the category 3 recommendations for person-centred support:

60. My support plan would take into account my coexisting conditions (if appropriate)
61. Support that takes into account my communication and contact preferences
62. Includes an individualised support plan that is tailored to my needs
63. My support plan would include personalised coping strategies
64. My support plan would take a holistic approach that looks at the whole person
65. Opportunity to access services when I need them
66. Support from an occupational therapist to understand my sensory profile
67. Begins at a point that feels right for me post-diagnosis
68. My support plan would take into account past trauma (if appropriate)
69. Flexible option to enrol in services and access support that appeals to me
70. My support plan would take into account my age
71. Blended support (face-to-face and/or online delivery)
72. Regular check-ups with a professional
73. My support plan would take into account whether I identify as LGBTQ+
74. My support plan would take into account my gender identity
75. Includes help to access education, health and care plans for over 25s
76. Accommodates missed attendance
77. Specialist autism physical health teams
78. Specific support with disordered eating
79. Includes help to apply for an education, health and care plan (if under 25)
80. Support with healthy living
81. Health monitoring with a professional
82. My support plan would take into account my culture
83. Access to support appointments outside of working hours
84. Specific support for womens' health issues
85. Drop-in sessions
86. Specific support for mens' health issues
87. My support plan would take into account my religious beliefs

Here are the category 4 recommendations for practical support:

88. Help to identify and obtain reasonable adjustments with employers
89. Sensory-friendly event spaces
90. Neurodiversity workplace training and awareness
91. Help with understanding what benefits I am entitled to
92. Information about Access to Work (publicly funded employment support programme that aims to help more disabled people start or stay in work)
93. Specialist neurodiverse people in HR and people development teams at work
94. Help with accessing benefits
95. Specialist neurodiverse assessors and companies providing the support for Access to Work
96. Help advocating for my safety and wellbeing
97. Help with understanding my legal rights in all areas of life
98. Help to find a job role that would better suit me, without losing significant salary
99. Help with maintaining employment
100. Help from a specialist neurodiverse team within the benefits system
101. Access to a quiet room
102. Help with financial aid for specialist equipment e.g. noise-cancelling headphones
103. Help with securing appropriate environmental adjustments
104. Help finding and approaching companies that make hiring autistic people a priority
105. Help to manage at college/university
106. Help finding employment that does not lead to burnout
107. Help to agree accommodations and alterations to the way that college/university modules and assignments are worded/written
108. Help finding employment consistent with my level of qualification
109. Help with gaining employment
110. Help finding a suitable career to match my profile of strengths and support needs
111. Help with maintaining a home and tenancy
112. Help with finding and securing appropriate housing
113. Help with applying for a council tax reduction
114. Autism-friendly times in museums
115. Autism-friendly cinema screenings
116. Information for parents on supporting children's education
117. Help with individual financial needs
118. Help with accessing benefits for an adult family member
119. Help with paying bills
120. Careers advice
121. Help to gain qualifications
122. Hidden disabilities sunflower lanyard scheme (wearing a sunflower lanyard discreetly indicates that you might need additional support)
123. Help with banking
124. Volunteer opportunities
125. Autism-friendly times in supermarkets
126. Help finding a graduate job

Here are the category 5 recommendations for support understanding autism:

127. Help to understand and accommodate sensory sensitivities
128. Help with information processing strategies
129. Help with understanding masking for autistic people
130. Employer-focused information that outlines the strengths of autistic employees as well as challenges
131. Access to free online resources
132. Help with understanding masking for my existing network of friends/family/professionals/colleagues
133. Autism post-diagnosis workshops
134. Information on experiences common to autistic people
135. Groups on understanding autism for my existing network of friends/family/professionals/colleagues
136. Groups on understanding autism for autistic people
137. Professionally recommended easy read materials (if appropriate)
138. Access to educational resources for my existing network of friends/family/colleagues
139. Guidance on talking to others
140. Professionally recommended book/website list
141. Guidance on making phone calls

Here are the category 6 recommendations for supporting relationships:

142. Guidance on how to support individuals/family members with chronic burnout and/or withdrawal
143. Opportunities to meet other autistic people
144. Directs me to groups within my local community to support me
145. Introduction to social groups for autistic people in my area when newly diagnosed
146. Help with supporting other neurodivergent family members
147. Support geared towards parents of late diagnosed young adults
148. Family support to include parenting advice and guidance
149. Support to manage family dynamics
150. Family support specific to parenting autistic children/adults
151. Includes an autism assessment for family members who want one
152. Opportunities to meet other people
153. Family therapy