

Autism Service Survey Results

Responses to survey: 45

How old are you? (100% response rate)

Option	Total	Percent
Under 11 years old	5	11.11%
12-15 years old	0	0.00%
16-25 years old	8	17.78%
26-34 years old	9	20.00%
35-44 years old	10	22.22%
45-54 years old	9	20.00%
55-64 years old	3	6.67%
65-74 years old	0	0.00%
75-84 years old	1	2.22%
85+	0	0.00%
Prefer not to say	0	0.00%
Not Answered	0	0.00%

How would you describe your gender identity? (100% response rate)

Option	Total	Percent
Male	23	51.11%
Female	19	42.22%
Non-binary	2	4.44%
Another description	0	0.00%
Prefer not to say	1	2.22%
Not Answered	0	0.00%

How would you describe your ethnic origin? (95.5% response rate)

Options White	Total	Percent
White - British	38	84.44%
White - Irish	2	4.44%
White - Gypsy or Irish Traveller	0	0.00%
White - European	3	6.67%
Other - White background	0	0.00%
Not Answered	2	4.44%

Options Mixed/Multiple Groups	Total	Percent
Mixed/multiple groups - White and Black Caribbean	0	0.00%

Mixed/multiple groups - White and Black African	0	0.00%
Mixed/multiple groups - White and Asian	0	0.00%
Mixed/multiple groups - Other mixed background	1	2.38%
Not Answered	41	97.62%

Options Asian/Asian British	Total	Percent
Asian/Asian British - Indian	1	2.22%
Asian/Asian British - Pakistani	0	0.00%
Asian/Asian British - Bangladeshi	0	0.00%
Asian/Asian British - Chinese	0	0.00%
Asian/Asian British - Other Asian background	0	0.00%
Not Answered	44	97.78%

Options Black/Black British	Total	Percent
Black/Black British - African	0	0.00%
Black/Black British - Caribbean	0	0.00%
Black/Black British - Any other Black/African/Caribbean background	0	0.00%
Not Answered	45	100.00%

Options Other Ethnic Group	Total	Percent
Other ethnic group - Arab	0	0.00%
Other ethnic group - Prefer not to say	0	0.00%
Other ethnic group - Other ethnic group	0	0.00%
Not Answered	45	100.00%

What part of Havering do you live in or live closest too? (100% response rate)

Option	Total	Percent
Collier Row	5	11.11%
Cranham	2	4.44%
Elm Park	4	8.89%
Harold Hill	7	15.56%
Harold Wood	4	8.89%
Havering-atte-Bower	0	0.00%
Hornchurch	5	11.11%
Noak Hill	1	2.22%
Rainham	4	8.89%
Romford	6	13.33%
South Hornchurch	0	0.00%
Upminster	4	8.89%
Wennington	0	0.00%
Prefer not to say	3	6.67%
Not Answered	0	0.00%

Where are you on your diagnosis journey? (100% response rate)

Option	Total	Percent
I have been clinically diagnosed with Autism	35	77.78%
I am waiting for an assessment	10	22.22%
Not Answered	0	0.00%

When did you receive your diagnosis? (Answers applicable to 35 out of 45 responses)

Option	Total	Percent
6-12 months ago	7	15.56%
1-2 years ago	5	11.11%
3-4 years ago	8	17.78%
5 years +	15	33.33%
Not Answered	10	22.22%

How did you find your diagnosis journey?

Common themes include:

- Waiting times for diagnosis are too long
- Instructions on how to obtain a diagnosis are unclear
- GP's are being considered as barriers to getting a diagnosis
- There is no support once diagnosed
- Lack of communication and understanding between partner agencies

How long have you been waiting for your autism assessment? (Answers applicable to 10 out of 45 responses)

Option	Total	Percent
0-6 months	4	8.89%
7-11 months	3	6.67%
1 year	1	2.22%
2 years	0	0.00%
3 years+	2	4.44%
Not Answered	35	77.78%

Are you receiving support while you are waiting for the assessment? (Answers applicable to 10 out of 45 responses)

Option	Total	Percent
Yes	1	2.22%
No	8	17.78%
Not required	1	2.22%
Not Answered	35	77.78%

If No, what would support you whilst you are waiting for your assessment?

Common themes include:

- Being given updates during the process would be useful
- Having someone to speak as have no one to ask
- Better understanding in the workplace
- Help with loneliness and social isolation
- Access to more groups or place to go for help and support

Which currently best describes your education and employment status? (100% response rate)

Option	Total	Percent
Mainstream School	6	13.33%
Additionally Resourced Provision (ARP)	1	2.22%
Special School	1	2.22%
Home Schooled	0	0.00%
Mainstream College	1	2.22%
Specialist College	1	2.22%
Apprenticeship or Internship	1	2.22%
Volunteering	4	8.89%
Full or part-time employment	15	33.33%
Unemployed	7	15.56%
Retired	3	6.67%
None of these	0	0.00%
Other	5	11.11%
Not Answered	0	0.00%

Other answers:

- Student
- Mainstream school with a hearing impaired unit
- On disability benefit
- Seasonal temporary job
- Awaiting school placement

Do you receive support in school, college or your workplace? (Answers applicable to 30 out of 45 responses)

Option	Total	Percent
Yes	16	35.56%
No	14	31.11%
Not Answered	15	33.33%

If Yes, are you happy with the level of support you receive?

Common themes include:

- Support is present in most schools and workplaces and adjustments are available
- Better general knowledge and understanding of autism would make further improvements

If No, do you think you would benefit from support and if so, what would this look like?

Common themes include:

- More understanding and acceptance, considering options to do things in a neurodivergent way
- Help with socialising and communicating
- Autism training for managers
- Access to advocacy and for people to listen

Do you access any community groups or activities? (100% response rate)

Option	Total	Percent
Yes	14	31.11%
No	31	68.89%
Not Answered	0	0.00%

Which groups or activities do you attend and what do you like about them?

Common answers:

- Sycamore Trust Peer and Steering Groups
- Havering MIND groups

Do you like engaging in activities with other people with autism? (100% response rate)

Option	Total	Percent
Yes	14	31.11%
No	7	15.56%
Sometimes	11	24.44%
Don't know/ Not applicable	13	28.89%
Not Answered	0	0.00%

What types of community support would you like to see in Havering?

Common themes include:

- More support for parents of autistic children
- More autism friendly activity groups that are available at different days and times to be more accessible

- Better help with social isolation
- Better autism awareness and education
- Post-diagnostic support
- Better information, advice and practical help when approaching GP's, employers, schools and colleges etc.
- Better support with gaining and maintaining employment

What are your top three priorities for our autistic community?

Priority 1

Common themes include:

- Better support with mental and physical health
- Better support with social inclusion including access to social groups, learning social skills and gaining independence
- Better autism awareness including mandatory autism training for all front line services across health, social care and education
- Better employment support

Priority 2

Common themes include:

- Better access to advice and information including 1:2:1 sessions and learning life skills
- Better autism and disability awareness in schools, including educating children on neurodiversity
- Access to more activities
- Better support with access to suitable accommodation
- Reduce waiting times for diagnosis and make the referral process easier

Priority 3

Common themes include:

- Support with anxiety
- Better support with finances
- Having autistic input into services
- Dedicated autism friendly spaces

Is there anything else you want to tell us to help us better support our autistic community?

Common themes include:

- Access to a befriending service for adults
- Better support for adults over the age of 25, especially those with additional needs
- Better support post diagnosis and better cooperation between NELFT and the NHS

- Access to nominated case worker for each person to improve communications across organisations
- Access to pre-diagnosis check ins whilst waiting for assessment

Parent and Carer Autism Service Survey Results

Responses to survey: 104

Who is completing this survey? (100% response rate)

Option	Total	Percent
Parent	95	91.35%
Carer (including Foster Carer)	2	1.92%
Family Member	6	5.77%
Children's Home	0	0.00%
Other	1	0.96%
Not Answered	0	0.00%

How old is your child or the person you care for? (100% response rate)

Option	Total	Percent
0-4 years old	12	11.54%
5-11 years old	37	35.58%
12-15 years old	16	15.38%
16-25 years old	31	29.81%
26-34 years old	5	4.81%
35-44 years old	0	0.00%
45-54 years old	3	2.88%
55-64 years old	0	0.00%
65-74 years old	0	0.00%
75-84 years old	0	0.00%
85+	0	0.00%
Prefer not to say	0	0.00%
Not Answered	0	0.00%

Which best describes the gender identity of your child or person you care for? (100% response rate)

Option	Total	Percent
Male	65	62.50%
Female	35	33.65%
Non-binary	1	0.96%
Another description	1	0.96%
Prefer not to say	2	1.92%
Not Answered	0	0.00%

How would you describe your child or person you care for's ethnic origin? (100% response rate)

Options White	Total	Percent
White - British	81	77.88%
White - Irish	0	0.00%
White - Gypsy or Irish Traveller	1	0.96%
White - European	1	0.96%
Other - White background	1	0.96%
Not Answered	20	19.23%

Options Mixed/Multiple Groups	Total	Percent
Mixed/multiple groups - White and Black Caribbean	3	2.88%
Mixed/multiple groups - White and Black African	6	5.77%
Mixed/multiple groups - White and Asian	4	3.85%
Mixed/multiple groups - Other mixed background	3	2.88%
Not Answered	88	84.62%

Options Asian/Asian British	Total	Percent
Asian/Asian British - Indian	0	0.00%
Asian/Asian British - Pakistani	1	0.96%
Asian/Asian British - Bangladeshi	1	0.96%
Asian/Asian British - Chinese	0	0.00%
Asian/Asian British - Other Asian background	0	0.00%
Not Answered	102	98.08%

Options Black/Black British	Total	Percent
Black/Black British - African	3	2.88%
Black/Black British - Caribbean	0	0.00%
Black/Black British - Any other Black/African/Caribbean background	0	0.00%
Not Answered	101	97.12%

Options Other Ethnic Group	Total	Percent
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Other ethnic group - Arab	0	0.00%
Other ethnic group - Prefer not to say	0	0.00%
Other ethnic group - Other ethnic group	0	0.00%
Not Answered	104	100.00%

Option Prefer Not to Say	Total	Percent
Yes	2	1.92%
No	102	98.08%

What part of Havering does your child or person you care for live in or close to?
(100% response rate)

Option	Total	Percent
Collier Row	11	10.58%
Cranham	4	3.85%
Elm Park	4	3.85%
Harold Hill	12	11.54%
Harold Wood	3	2.88%
Havering-atte-Bower	1	0.96%
Hornchurch	32	30.77%
Noak Hill	0	0.00%
Rainham	9	8.65%
Romford	19	18.27%
South Hornchurch	2	1.92%
Upminster	6	5.77%
Wennington	0	0.00%
Prefer not to say	1	0.96%
Not Answered	0	0.00%

Where is your child or person you care for on their diagnosis journey? (100% response rate)

Option	Total	Percent
They have been clinically diagnosed with Autism	95	91.35%
They are waiting for an assessment	9	8.65%
Not Answered	0	0.00%

When did your child or person you care for receive their diagnosis? (Answers applicable to 95 out of 104 responses)

Option	Total	Percent
6-12 months ago	20	19.23%
1-2 years ago	16	15.38%
3-4 years ago	17	16.35%
5 years +	42	40.38%

Not Answered	9	8.65%
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How did you and your child or the person you care for find their diagnosis journey?

Common themes include:

- Waiting times for diagnosis are too long leading to some children reaching crisis point mentally and physically resulting in some families paying for a private assessment
- Instructions on how to obtain a diagnosis are unclear and complex, only those working in the health sector understood what to do
- Lots of initial misdiagnoses with families having to complain to receive a second opinion
- Lack of communication from and between professionals whilst awaiting diagnosis
- No information and advice readily available, most sort support through First Steps, informal coffee mornings and online support groups
- Support from schools is inconsistent

How long has your child or person you care for been waiting for an autism assessment? (Answers applicable to 9 out of 104 responses)

Option	Total	Percent
0-6 months	2	1.92%
7-11 months	0	0.00%
1 year	1	0.96%
2 years	5	4.81%
3 years+	1	0.96%
Not Answered	95	91.35%

Has your child or person you care for been receiving support whilst waiting for their assessment? (Answers applicable to 9 out of 104 responses)

Option	Total	Percent
Yes	5	4.81%
No	4	3.85%
Not required	0	0.00%
Not Answered	95	91.35%

If No, what would support them whilst they are waiting for their assessment?

Common themes include:

- Having an EHCP in place
- Help with getting access to employment/benefits

Which currently best describes your child or person you care for's education and employment status? (100% response rate)

Option	Total	Percent
Mainstream School	45	43.27%
Additionally Resourced Provision (ARP)	5	4.81%
Special School	10	9.62%
Home Schooled	1	0.96%
Mainstream College	9	8.65%
Specialist College	1	0.96%
Apprenticeship or Internship	1	0.96%
Volunteering	2	1.92%
Full or part-time employment	2	1.92%
Unemployed	9	8.65%
Retired	0	0.00%
None of these	3	2.88%
Other	16	15.38%
Not Answered	0	0.00%

If Other, please tell us more

Common themes include:

- Nursery/Pre-school
- University

Does your child or person you care for receive support at school, college or their workplace? (Answers applicable to 75 out of 104 responses)

Option	Total	Percent
Yes	64	61.54%
No	11	10.58%
Not Answered	29	27.88%

If Yes, are you and your child or the person you care for happy with the support they receive?

Common themes include:

- Happy in general if child attends a special school, has an EHCP and or 1:1 support but there are still areas of need
- Mainstream schools are caring but cannot meet the children's needs lead to inconsistent support

If No, do you think your child or person you care for would benefit from support and if so, what would this look like?

Common themes include:

- Speech and language therapy

- Working with local businesses to encourage them to offer positions to young people on the spectrum
- Support with law and employment law
- Something in place to help recognise and understand triggers
- More help and guidance overall

Does your child or person you care for access any community groups or activities?
(100% response rate)

Option	Total	Percent
Yes	39	37.50%
No	65	62.50%
Not Answered	0	0.00%

Which groups or activities does your child or person you care for attend, and what do they like about them?

Common answers include:

- First Step family sessions
- Sycamore Trust peer groups
- SEN swimming sessions
- SEN sessions in Romford and Upminster
- FIG holiday clubs however very oversubscribed
- Activities arranged through RAGS
- PARA art classes
- Brownies/Beavers/Guides/Scouts

Does your child or person you care for enjoy engaging in activities with other people with autism? (100% response rate)

Option	Total	Percent
Yes	22	21.15%
No	24	23.08%
Sometimes	32	30.77%
Don't know/ Not applicable	26	25.00%
Not Answered	0	0.00%

What types of community support would you and your child or person you care for like to see in Havering?

Common themes include:

- Youth clubs for older children/teenagers, targeting those at transition age
- Designated play areas

- Better understanding and support at school including teachers undertaking mandatory autism awareness training and for all children to learn about neurodiversity
- Quiet safe spaces in public places
- LD/Autism structured activity groups for all ages including from toddler age available after school and on weekends (not necessarily arts and crafts focused)
- Groups for those over 30
- More information and advice specifically to support those with autism
- More mental health support targeting managing anxiety and low mood
- Respite facilities
- More SEN sports activities with limited numbers to reduce crowds i.e. swimming, football, gymnastics, dance classes etc
- Better advice and information including, parent coffee mornings life skills, mentoring, career advice and access to apprenticeships
- Pre-diagnostic support to guide families through the assessment process
- Further funding for First Steps and other charities that already support the autistic community

What are your top priorities for our autistic community?

Priority 1

Common themes include:

- Better support with mental and physical health
- Better access to information and advice, suggested dedicated website page on Havering website
- Better support with social inclusion and gaining independence and confidence
- Access to pre and post diagnostic support
- Better support with transition to adulthood
- Activities available at weekends and school holidays
- Better support in education and routes to employment
- Quicker routes for diagnosis
- More targeted sports activities
- Better support in schools including all teachers undertaking mandatory autism awareness training
- Better communication between health and social care services

Priority 2

Common themes include:

- More parental resources to manage at home
- More specialist schools
- Process of applying for EHCP's should be clearer and not so difficult to obtain
- Better autism awareness and understanding in the wider community
- Better help with routes into employment, apprenticeships schemes etc

Priority 3

Common themes include:

- Better support with access to housing and suitable accommodations
- More social groups for all ages at regular fixed times
- A single point of contact for parents of children with high needs
- Autism targeted events to bring the community together

Is there anything else you want to tell us to better support our autistic community?

Common themes include:

- More experienced professionals to support the autistic community
- Co-produced groups run by parents and carers
- More CAHMS support
- Wider advertising on what is currently available
- More local short break providers
- Sensory rooms in hospitals and schools