healthwatch
Havering

Community Engagement

Services for people living with learning disability and autism

A review of the views of service users, their carers and associated professionals

August 2023

Healthwatch Havering is the operating name of
Havering Healthwatch Limited
A company limited by guarantee
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What is Healthwatch Havering?

Healthwatch Havering is the local consumer champion for both health and social care in the London Borough of Havering. Our aim is to give local citizens and communities a stronger voice to influence and challenge how health and social care services are provided for all individuals locally.

We are an independent organisation, established by the Health and Social Care Act 2012, and employ our own staff and involve lay people/volunteers so that we can become the influential and effective voice of the public.

Healthwatch Havering is a Community Interest Company Limited by Guarantee, managed by three part-time directors, including the Chairman and the Company Secretary, supported by two part-time staff, and by volunteers, both from professional health and social care backgrounds and lay people who have an interest in health or social care issues.

Why is this important to you and your family and friends?

Healthwatch England is the national organisation which enables the collective views of the people who use NHS and social services to influence national policy, advice and guidance.

Healthwatch Havering is your voice, enabling you on behalf of yourself, your family and your friends to ensure views and concerns about the local health and social services are understood.

Your contribution is vital in helping to build a picture of where services are doing well and where they need to be improved. This will help and support the Clinical Commissioning Groups, NHS Services and contractors, and the Local Authority to make sure their services really are designed to meet citizens' needs.

'You make a living by what you get,
but you make a life by what you give.'
Winston Churchill

Community engagement

Under Section 221 of the Local Government and Public Involvement in Health Act 2007, Healthwatch Havering has a statutory duty to ascertain the views of health and social care services and to make them known to the commissioners and providers of those services so that they can be taken into account in the development, commissioning and delivery of services.

We do this in a variety of ways, such as surveys, interviews and focus groups.

We also participate, with other Healthwatch organisations across North East London, in the Community Insights System, which gathers views and comments on health and social care from people across the area. Intelligence gained from Community Insights is used directly in, or to inform, many of the surveys and other public engagement events that we carry out.

The results of our community engagement are shared with Havering Council, NHS North East London, NHS and other provider organisations and Healthwatch England.

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In the following text, the paragraphs that begin with an arrow (➢) are quotations taken from the actual responses we received during our meetings and surveys.

Glossary of terms used in this report

This is an extensive report, with numerous abbreviations and acronyms, some familiar and some not so. For ease of reference, those most used are listed here:

Acorn Centre – a community facility provided by NELFT

ADHD – Attention Deficit Hyperactivity Disorder

ADOS – Autism Diagnostic Observation Schedule

ASD – Autism Spectrum Disorder

Avelon – a day care facility in Avelon Road, Hornchurch

A&E - Accident and Emergency, generally at Queen's Hospital, Romford

BOSP – Brighter Opportunities for Special People

CAD – Children and Adults with Disabilities

CAMHS – Child and Adolescent Mental Health Service (in Havering provided by NELFT)

CHC – Continuing Health Care (an NHS service)

CLDT – Community Learning Disability Team (provided jointly by Havering Council and the NHS)

DCD – Development Co-ordination Disorder

DLA – Disability Learning Allowance (a social security benefit)

DP – Direct Payment (a social security benefit)

DWP – Department of Work and Pensions (a government ministry, responsible for social security benefits)

EHCP – Education and Health Care Plan (formerly a Statement of SEN)

ESA – Employment and Support Allowance (a social security benefit)

HAF – Holiday activities and food programme

HLDS – Havering Learning Disability Society

Hospital Passport – a document identifying the bearer as someone for whom priority service is necessary (for example, as living with a learning disability or autism, or a vulnerable older person)

ICB – Integrated Care Board (also known as NHS North East London)

LD – learning disability

LD/A – learning disability and autism

L&Q – London & Quadrant Housing Association

Makaton – a form of sign language devised for people who are non-verbal

NAS – National Autistic Society

NELFT – the NHS body responsible for providing a range of community clinical services, including paediatric support and mental health services

Non-verbal – people who are unable to communicate by speaking

OT – Occupational Therapy (or Therapist)

PA – personal assistant

PDA - Pathological Demand Avoidance

PIP – Personal Independence Payment (a social security benefit)

SEN – Special Educational Need

SEND – SEN and Disability

Sibs – a charity supporting people who grow up with or have grown up with a disabled brother or sister. It is the only UK charity representing the needs of over half a million young siblings and over one and a half million adult siblings

TA – Teaching Assistant (in school)

TLC – The Learning Centre (a local private provider of day care for people living with a learning disability)

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Introduction

In November 2022, the Havering Place-based Partnership commissioned Healthwatch Havering to find out what people thought about services in Havering provided for people who are living with learning disability and/or autism.

The terms “learning disability” and “autism” have generally pejorative associations. This is mainly because people living with them tend to come to the attention of much of the public only occasionally, usually because such disabilities can make interaction with others difficult.

The terms cover a huge range of conditions, from minor cognitive problems to major disability rendering the affected individuals extremely vulnerable and unable to function on an everyday basis. The public often confuse the terms with poor mental health – ignoring the fact that an individual with a high degree of learning disability or autism may be nonetheless mentally healthy whilst most people with poor mental health are unlikely to be autistic or living with a learning disability. As so often in other fields, the lack of awareness among the public gives rise to profound misconceptions and misunderstandings.

For this project, we decided to try to find out what service users, their friends, families and other informal carers and professionals working in related fields thought about the

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services on offer for those service users. We arranged discussions with them and a survey of their views.

At the outset, we were expecting a high level of engagement, since anecdotally many people feel that the services they receive from the health and social care system are inadequate. We were surprised to find, however, that despite the negative atmosphere, far fewer numbers were prepared to engage with us than we had anticipated.

In part this may have been because the financial pressures on individuals because of the current financial climate have left them with little time to get more deeply engaged in projects such as ours. There is also some evidence that some people living with autism or a learning disability are unable to access mainstream communications and that may also apply to their immediately family as well.

We have nevertheless proceeded with the project as best we could in the expectation that the outcome of our project will nevertheless assist NHS North East London and Havering Council determine the future shape of services in Havering for this client group.

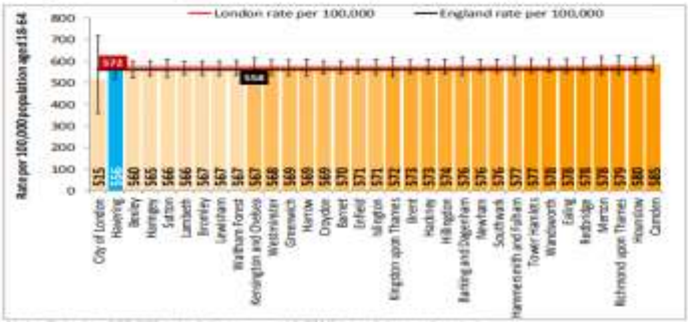
In addition to direct contact with disabled people and those who support them, we have used data obtained thorough the Healthwatch North East London Community Insights System.

Demographics

Based on the 2021 census, the current population of the borough is about 262,000 and is projected to grow over the next few years to around 295,000 as more housing development takes place across the borough. Havering remains the London borough with the greatest number of residents over the age of 65 and, despite a growth in those below that age range, that is expected to remain the case over the next 20 years. Untypically for both North East London and London as a whole, some 81% of the population was born in the UK (the vast majority in England) with those born elsewhere than in Europe comprising 10.6% of the population, of whom most came from the Middle East and Asia. Very few Havering residents are unable to speak English and over 90% have English as their first language.

The following chart is taken from Havering Council's online publication **This is Havering 2019**[1]:

Figure 23: Estimated moderate or severe learning disabilities rate per 100,000 persons aged 18-64 years, in Havering and other London boroughs, London and England, 2017



Note: Rate per 100,000 calculations use mid 2016 population estimates
Data Source: Projecting Adult Needs and Service Information System (PANSI, 2017); calculations uses Mid-year population estimates 2016: Office for National Statistics (ONS); Produced by Public Health Intelligence

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[1] https://www.haveringdata.net/wp-content/uploads/jsna/this_is_havering/201819_Havering-Demographic-Profile-v4_2.pdf

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In 2015, it was estimated that some 19% of working age people in Havering were living with some form of disability or long-term illness. Of that population, about 820 people aged 18-64 had a moderate or severe learning disability, with the borough having the 3rd lowest rate of such disability in London.

The number of people living with any form of autism or learning disability is, therefore, clearly a very small proportion of the population of the borough. That is, however, not to say that their needs can be overlooked: on the contrary, given that they rightly expect to be able to live the fullest lives possible, they need additional help to ensure that they are able to live a reasonable life and, where possible, make a positive contribution to the life of the community.

What people told us

During this project, we met a few service users with autism or a learning disability and with those caring for them; we also met representatives of voluntary organisations including the Sycamore Trust and Positive Parents. We also visited services for adults requiring support and personal care. They provided us with useful background information as well as contributing by completing our online survey. They responded openly and honestly to our enquiries. We also met others who helped them, including representatives of each of the Primary Care Networks in the borough.

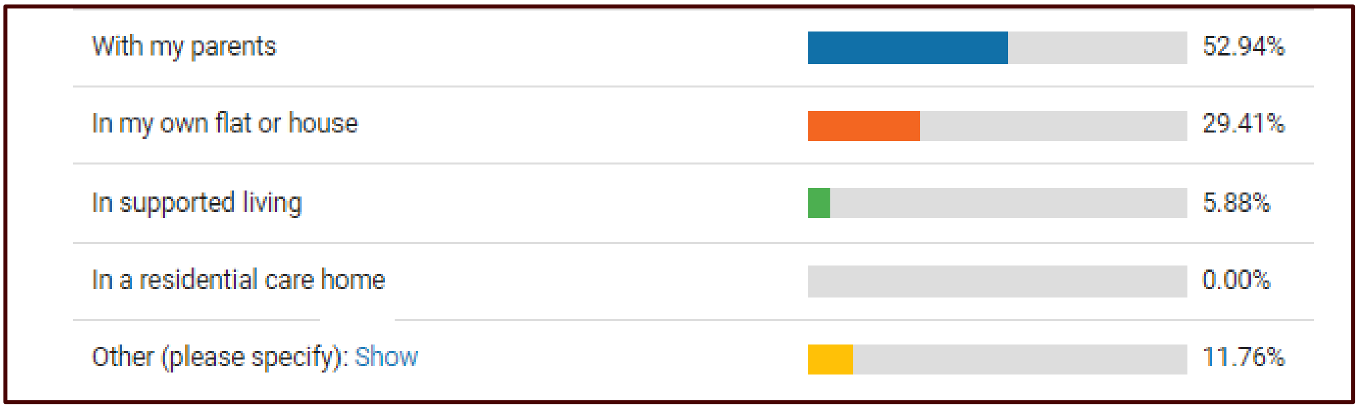
We also invited people to complete an online survey to give us their views. There were three such surveys, one for service users, one for friends, family and other informal carers and one for professionals.

For the purposes of this report, we have set out the responses we received from the three groups of respondents. Within each group, the responses are arranged by theme and then by survey question. The charts show the responses in a numerical format while the paragraphs that begin with an arrow (➢) are quotations taken from the actual responses – note: not all responses are accompanied by chart.

1 Service users

Theme: Meeting accommodation needs

We asked respondents to tell us where they live and about their living conditions. They replied:



With my parents	52.94%
In my own flat or house	29.41%
In supported living	5.88%
In a residential care home	0.00%
Other (please specify): Show	11.76%

Are you happy where you live?

- I don't feel safe.
- Unhappy with the workman that come round to do jobs that are needed. The work is very shoddy and is causing me a great deal of anxiety and stress to have to deal with these people. Neighbours are harassing me as they do not use their own keys to open the main door and expect me to keep letting them in and when I don’t, they keep pressing the intercom. This is very scary and I now need to move as it has been going on for many years.

Where would you like to live?

- Sheltered accommodation nearer to my mother in another part of Havering. I would like to move to Dreywood Court in Gidea Park.
- In social housing to give us stability and to meet my son's needs with a property that is suitable
- Somewhere greener on the edges of Essex.
- When I am older, I would like to live in fully supported living that is completely accessible and facilities for a fully reliant wheelchair user
- I would eventually like to live alone in my own accommodation and try and live more independently. Preferably somewhere in the same borough, Havering, so I

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can still have access to my local and current support networks.

Comment

More than half of the respondents told us they lived with parents and most were happy where they lived.

It should be borne in mind, however, that as parents grow older, they become less able to care for their child or children and, of course, they will eventually no longer be there to provide care.

While reaching expectations is difficult, people cared for by parents (or other relatives) need to be prepared for the changes that will be inevitable when those who care for them are no longer able to do so.

Theme: Employment issues

We then asked whether they were employed:

Do you have a job for which you get paid?

- Chef in a pub
- Bus electrician
- 2 days per week in a café
- Claims handler

If you do not have a job, would you like to get one?

- After my studies. Bus or train driver.
- receptionist cinema worker office worker cafe worker runner for television
- Helping people
- Graphic Designer.
- Dog groomer
- Has no idea
- Artist
- I said yes in a general term. I don't think I can do a normal job but in ideal circumstances, I would love my art and my designs to be my job
- Pub work
- No idea
- Baker or working in a café

Comment

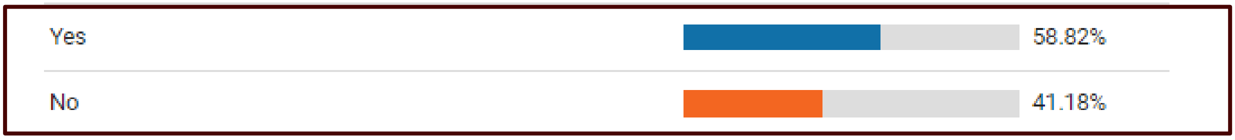
Although more than three quarters of respondents did not have any employment, well over half would like to work.

All the evidence available points to being engaged in some form of employment as encouraging independence and boosting wellbeing. Consideration should be given to setting up some form of agency able to place people with learning disabilities and/or autism in suitable employment.

Theme: Managing finances

One of the principal skills of everyday life, and essential to feeling independent, is managing your own money. Our respondents told us:

Do you get help looking after your money?



- My mum handles bill paying. I don't understand budgeting. I am not good or comfortable handling money. Working out change and counting it. I usually just pay by card on small purchases.

Are you happy with the help you get to look after your money?

- It is so difficult for my parents to access some of my money without a deputyship. **They are my parents and should have complete access to my money without all the rigmarole** *[emphasis added]*
- I would like to learn how to budget and about how to pay the bills. Learn how to confidently handle paying and counting cash.

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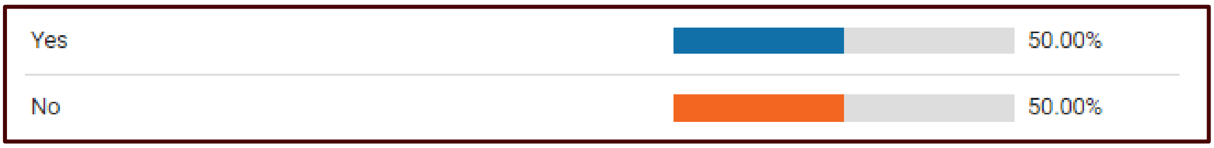
If you need help looking after your money, do you know where to go for help?



- My Mum and Dad. I couldn't do it on my own
- It is very difficult to get help with money issues in this borough.
- I wouldn't know who to ask. How that would work. Who could help me. I don't know.

Are you worried about the costs of living:

Shopping?

Energy – gas and electricity?

Care and Support?

Going out with friends or family?

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Comment

These responses suggest that more needs to be done to help people living with autism and learning disabilities to understand how to manage their money independently. It needs to be recognised, however, that some may not have the capacity to do that and accordingly they may need help from parents, other family members or trusted friends to do that.

For understandable reasons, there are strong legal safeguards in place to ensure that, for example, their funds are not subject to theft or fraud. Paradoxically, however, those safeguards disadvantage the very people they are meant to help by making access to money more difficult than it needs to be. [2]

Whilst dealing with that is outside the remit of this report, there is scope for exploring the extent to which it might be possible to relax the legal framework to facilitate access to money without compromising the essential safeguards.

Theme: Social activities

We asked about going out – freedom of movement is important for an individual's wellbeing:

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[2] For more information, go to: https://www.gov.uk/courts-tribunals/court-of-protection

Are you happy to go out on your own?

- I get anxious around dogs and birds and so many people.
- I go out shopping during the day but do not go out in the evenings. Socialising is very hard as there are no groups in this borough that are prepared to help people with a learning disability.
- I am only happy if I know I won't have to talk to anyone
- If there was a "sometimes" option, I would have put that. Sometimes I'm happy to go out in my own. But I have to take lots of fidget stuff and support items with me. Often, I am not happy to go out alone due to anxiety.
- I'm unable to go out on my own, always have to have someone to operate my electric wheelchair
- I am not good at travelling by myself and need help
- I cannot go out on my own due to mobility and I also have an intellectual disability

When you go out, are you easily able to access the places you want to go to?

- New places I would need travel training
- Better rules that people followed

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- Someone to help me when I get confused. I'm vulnerable outside my immediate home area
- Proper wheelchair access and wider door access
- Someone to support me
- sometimes I struggle with the noise and other sensory inputs
- Changing places!! As an incontinent wheelchair user who is unable to weight bear there are NO local changing facilities at all!!! This needs looking into.

Do you enjoy going to clubs?

- There are none in Havering
- It is very hard to socialise with people due to them not wanting to mix with people that have a learning disability.
- Depends on your meaning for clubs. If it's nightclubs, no because of noise, drink etc. If its regular clubs, well, I'd like to find one I can attend comfortably.
- Anxiety, worry. Transport/getting there. Being on my own etc.
- My concentration is not good enough and I don't like a lot of people around me
- Too loud and too much sensory input

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What clubs do you go to?

- None for now, because Mummy hasn't been well to take me there and I don't want other people to take me without Mummy
- I go to Sawyers Church Tuesday club in Brentwood I go to the HLDS on alternate Fridays. Both are charities and run by volunteers and no support from Havering council There is nothing else for people of my age
- Sycamore Trust in Romford
- Sycamore Trust 18-30's Group, Peer Group and Steering Group Bridge of Friends
- Drama and cricket
- I attend Havering Association for people with Disabilities (HAD) and Havering Mind.

Comment

Although most are happy to go out on their own and over half have easy access to the places they want to go, some are reluctant to do so.

The provision of clubs and other places of recreation is largely a matter for voluntary activity. Whilst that is both inevitable and right, the availability of clubs and safe and secure arrangements for getting to them for those that need such help should be more widely advertised though Adult Social Care.

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Comment - *continued*

It is disappointing to hear someone must travel to Brentwood for a club.

There is surely scope for the reinstatement of facilities such as “drop in cafes” that used to be provided in the borough.

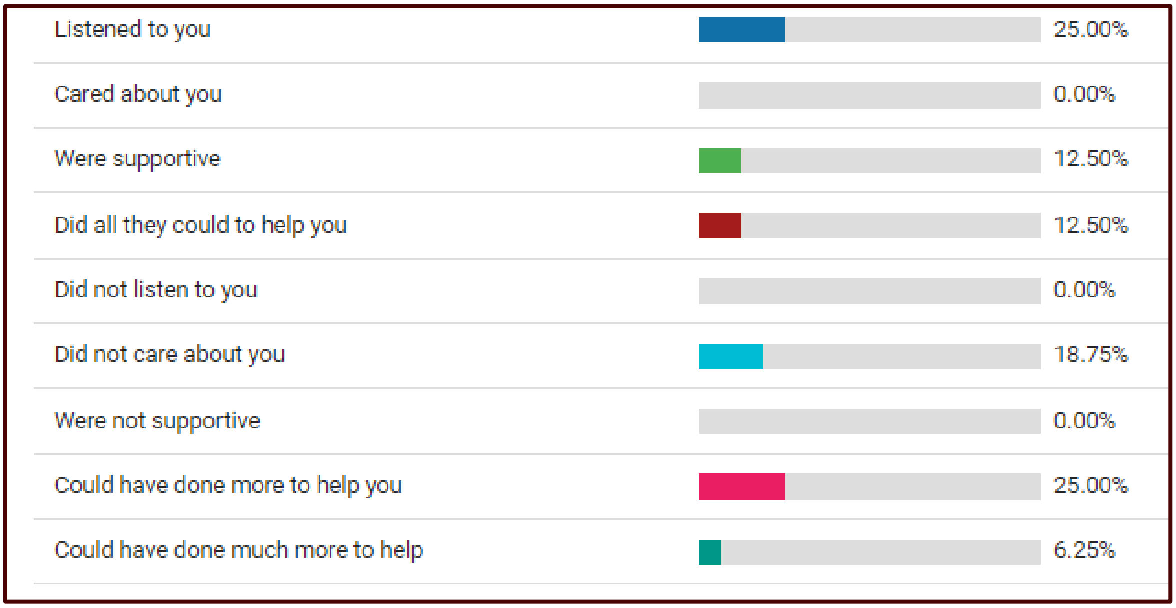
Theme: Experiences in a healthcare setting

We asked about their experiences of GP practices, hospitals and other healthcare settings:

When you have an appointment with your doctor, do you prefer:

- You do not get the option so have to have telephone calls.
- I like to see them and hand them a piece of paper with what I want to say in written form for them to read
- My mum has to speak for me because I am non-verbal
- Video

When you last spoke to the doctor or nurse, did you feel that they:



- [The] Receptionist has sniggered at me a few times which is very distressing and disrespectful. All staff should have LD awareness training, they have a duty of care to get medicine to me. **[I] told the GP [that I cannot have] BP tablets because [I have] falls in [my] flat. They still want me to take BP tablets and are not listening to me** *[emphasis added]*. [They] won't allow a separate number to call for LD patients. There should be a number for vulnerable patients to use.
- **I have to go with someone to my GP and even then, they talk to the other person not me** *[emphasis added]*. Other professionals do listen to me but I still have to have someone go with me
- And didn't listen to me as well
- This question is only allowing me to tick one of the boxes for how I felt during my last visit. I felt that even though they listened to what I had to say there was a lot of information

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to process which I found challenging. I had to take my mum into the appointment to speak on my behalf as I find it difficult to articulate my condition. **I felt that the nurse didn't fully understand how my autism affected the way I process what I was being told. They said to Mum let me speak and I'm not always able to so this which is why mum speaks for me** *[emphasis added]*.

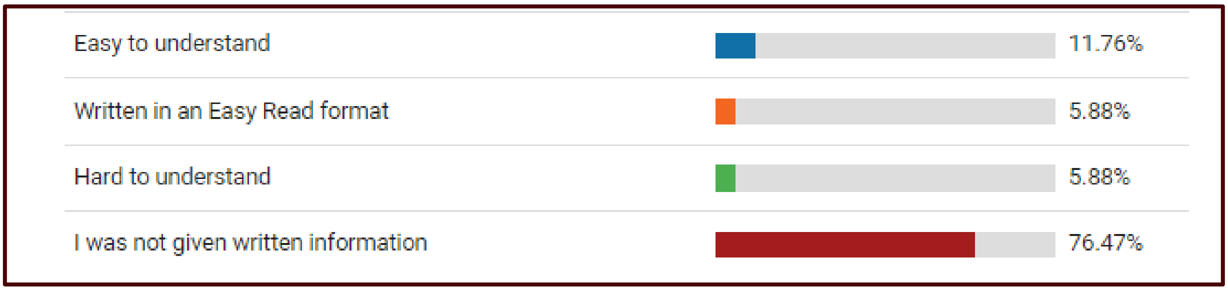
- I feel that I am not listened to so feel that I have to write a letter but even this still does not seem to work.
- I would tick listened to you, were supportive, could have done more to help you i.e. explain what they think
- I often feel that because I already have a number of health issues, that when something else crops up, I'm not listened to or I come across as a hypochondriac.
- **Like they cared** *[emphasis added]*
- Struggling to get assessed for ADHD
- I was told if I don't like the service to find a new surgery
- I rarely talk or try and contact my GP surgery. I feel like I am wasting their time. Since I have been diagnosed with Autism as an adult. I have received no support after diagnosis from GP or any other service.

Did you have enough time to explain what help or support you needed?

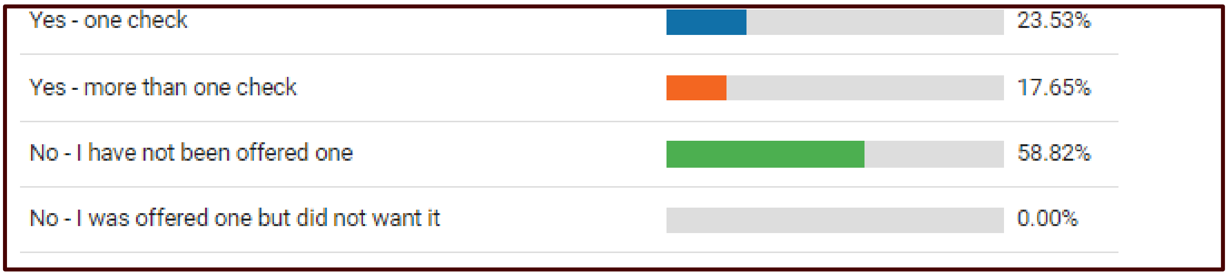
- Only because someone is with me

- Because of my autism
- To explain things properly
- **I haven't the time as I have to explain every time i speak with a Doctor** *[emphasis added]*
- I do not discuss with them my mental health and autistic needs with them. Previous GPs have only wanted to ask and discuss if I have a job and why I am not working. This causes me to become distressed and have a meltdown. Since my diagnosis, the GP has not discussed my diagnosis or my mental health needs. They just keep prescribing me my antidepressants. That's all.

If you were given written information about your treatment, was it:



Have you had an Annual Health Check since 2020?



- Once a year, with the nurse. This has been vital for me to get information about social group (Sycamore Trust) and not be isolated.

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Comment

In common with the public, all respondents would like to see a healthcare professional face to face. While acknowledging the difficulties being experienced by primary care, people living with learning disabilities and/or autism should however be given some priority. Some would find it difficult to conduct a phone call appointment.

It is disappointing to see that some respondents had negative experiences of appointments, especially in terms of being listened to and being allowed to speak up for themselves.

Evidence suggests that ALL staff in many GP practices need greater awareness of the difficulties faced by people living with learning disabilities and autism.

It is also very disappointing to note that more than half of the respondents have never been offered an annual health check and that 75% of respondents have not been offered written information about their treatment, especially as their conditions are likely to impair their ability to absorb information rapidly.

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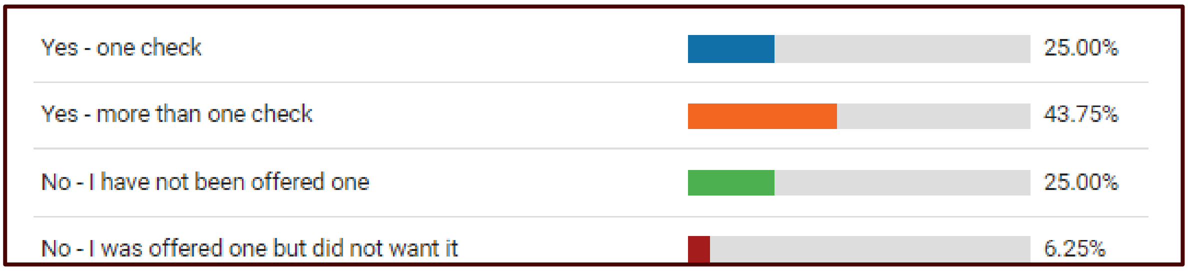
Comment - *continued*

It is sad to note the feeling of many that they are not listened to and unsupported. **No one should be told**:

"if [you] don't like the service … find a new surgery"

Theme: Experiencing dental services

Have you had a Dental Health Check since 2020?



- I am with South Hornchurch Health Centre and can only go there with a referral from the Hermitage Team. I do not have an NHS dentist for routine dental checks.

Comment

The problems of accessing NHS Dentistry is a national issue and it is not surprising that people with learning disabilities and autism are affected.[3]

That said, it is disappointing that most of our respondents have been unable to have a dental health check in recent years.

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[3] There is a page on the NHS website that can help locate an available dentist - https://www.nhs.uk/service-search/find-a-dentist

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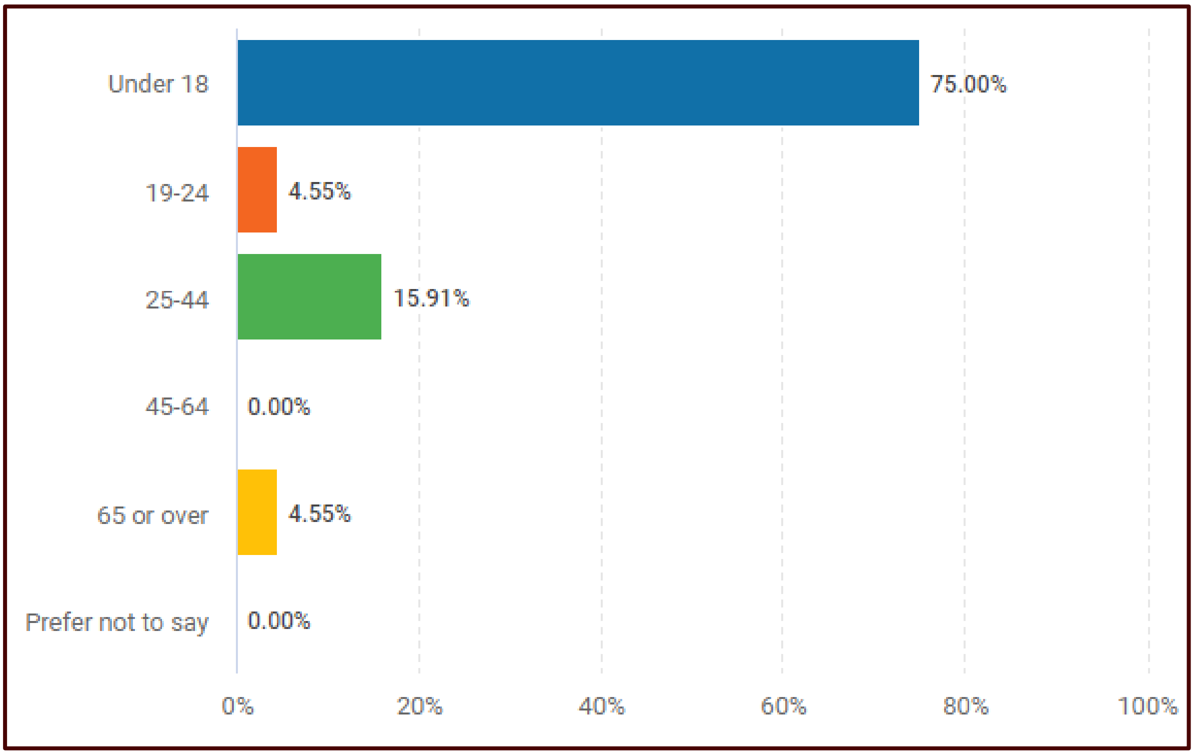
2 Family, friends and informal carers

Although we aimed our survey at those caring for people living with autism or a learning disability of any age, three quarters of those who responded were caring for someone under 18 years of age:



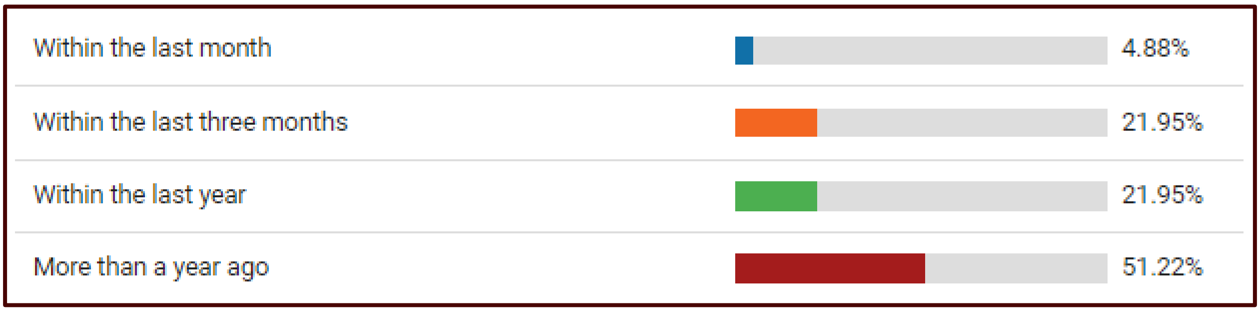
We asked respondents to tell us about their day-to-day living experiences (or the experiences of those they were caring for).

Theme: Experiences in a healthcare setting

If the person you care for is offered an annual health check with a GP, do they attend?

- My child is with the Acorn Centre and has annual appointments with them. Not the GP.
- He has it with the Acorn Centre paediatrician
- There is no healthcare check offered but there should be as it is difficult for autistic people to fully express themselves so if they are poorly, it is difficult to know why and what. A specific nurse should be in each surgery for the purpose of this check and if necessary, signpost them to the GP
- Support staff need to be reminded to make the referral
- Since diagnosis have had no interactions from the GP despite us initially contacting GP for us to be referred to SALT and audiology. There has not even been a follow up since diagnosis to see how we're coping or how child is coping or if they have any other co-morbidities etc
- I understand from NICE guidelines that this should be the case. I've enquired about it with the Acorn Centre paediatrician and was told this wasn't the case in Havering. I will be taking it up with my own GP practice to see if they will follow the guidelines.
- I had to remind my doctor to offer this appointment
- Not ever had health check but would be very difficult to get her to the doctors let alone be checked

When was their last health check?



Have their health checks led to health improvements?

- Acorn Centre (community paediatrician) should see them on 6 monthly basis. However, this never happens. Due to acute staff shortages at the Acorn Centre we never get our child seen by a Paediatrician regularly. COVID-19 was used as an excuse but what is the reason now in 2023?
- On going investigations as to why my daughter's health will be affected
- Unless you mean with the Acorn Centre aka Paediatrician, then the answer is slightly.
- They've never had a general health check
- Actions we requested at the most recent check do not appear to have led to the help we needed. For example, we have been asking the CLDT for counselling as my brother A is finding it very difficult to cope with the death of his mum, but the CLDT have yet to assign any counsellor despite regular enquiries on progress from me and have most

recently not responded even to emails asking for an update. We have been asking for many months, certainly more than 6 months ago. We mentioned A's needs for counselling at his check and the nurse promised to chase it up, which she may have but we haven't heard anything from either the doctors or the CLDT. So in terms of mental health, we have not seen the annual check lead to improvements yet. We have visited You & Me Counselling today to see if we can pay for help ourselves.

- In my opinion annual health checks are a waste of time. The practice nurse does it, not the GP. All the nurse does is take blood pressure. I insist that my daughter has a blood test prior to the check to make sure that everything is ok. They never listen to her heart or chest or weigh her because they only have bathroom scales which my daughter can't stand on. The ICB should purchase sit on scales and then when a practice knows that someone with LD is coming for check they could request to loan them. It would also be helpful to have a check list of what is supposed to happen and then this could be handed to the patient and a comparison made each year, this would be particularly helpful when the patient can’t verbalize and tell the GP about things that are or maybe wrong.

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Comment

Carers' comments support the service users' view that health checks are hard to come by, nor are they particularly effective.

It is not only about having an annual health check but about the quality of the check. This can help plan for the future and detect any healthcare problems sooner. For example, weight is a very serious matter that can, for example, influence the doses of some medication that should be taken.

Theme: Experiencing dental services

Is the person you care for offered an annual dental check?

If so, do they attend?

- I took him to a dentist and we are still awaiting the community dentist to get back to us for his tooth to be removed
- Our daughter cannot go to a dentist due to her needs. She also had all her baby teeth removed due to an enamel issue. We are currently trying to find a SEND friendly dentist.
- Again after attending the dentist once, the dentist was very good then he left the practice. Saw another who was awful

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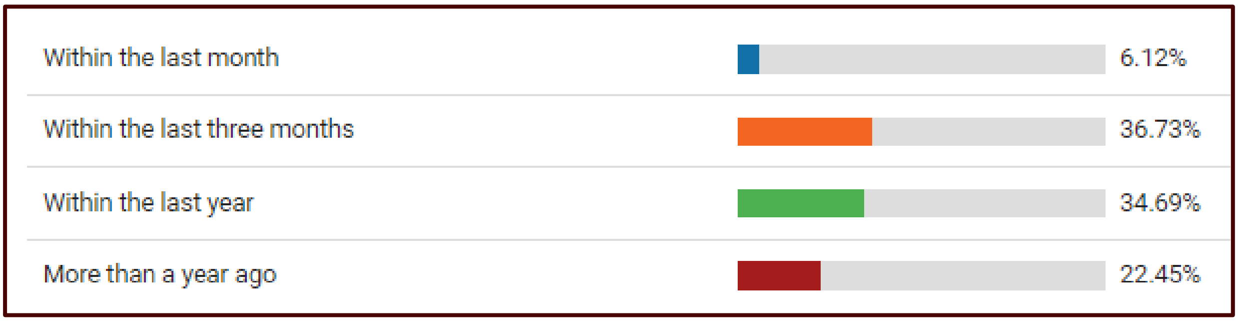
and told us to contact the specialist community dentist but for this needs a referral.

- I have arranged for my daughter to have a 6 monthly dental check with our neighbour (who is a dentist). This is helpful because she is a familiar person to my daughter. She still finds the experience very daunting and becomes very anxious. There has been no offer of Autism-aware dental practices from the local services at all.
- I would love to have someone help us with A's teeth - we are good at brushing etc but they are quite yellow and it would be helpful to have a professional clean. Having taken over care from A's mum following her death, there are a few things like this that me and A's sisters are not sure what to do about, but certainly we've not had any letters about a check-up I can respond to.
- My daughter goes every 4 months because I insist.

When was their last dental health check?



Within the last month	6.12%
Within the last three months	36.73%
Within the last year	34.69%
More than a year ago	22.45%

Comment

While accepting that a visit to the dentist is disconcerting for many people, it would be useful to identify dental practices that are “learning disability and autism friendly.”

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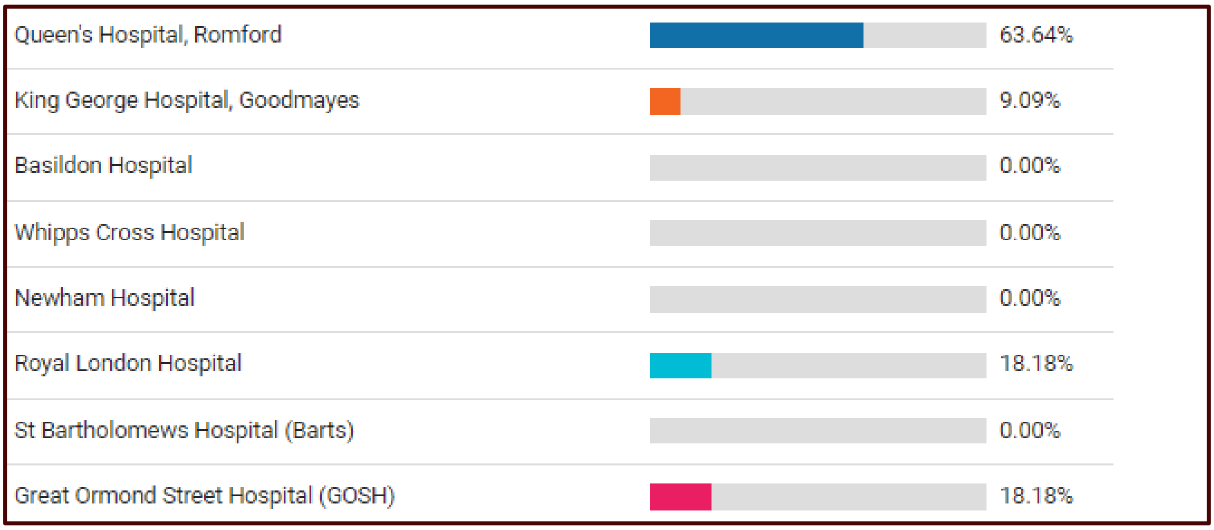
Theme: Experiences in a hospital setting

Has the person you care for been an in-patient in hospital in the last three years?

In which hospital?



Thinking about the hospital at which they were an in-patient for the longest time, how well do you think their specific needs were met?

- We did MRI in Queens Hospital. They booked my daughter at 2pm and she wasn't supposed to eat anything before that. Then we were waiting for another 3 hours in hospital. I told staff that she has autism, she doesn't understand, she's non-verbal. They ignored me until she started to scream like crazy.

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- Every hospital needs to learn a lot more about Autism and how it impacts each individual as every autistic person has very specific needs and no two autistic people are the same. More training for the entire medical and non-medical personnel is very much needed. More funding needs to be directed to this specific need in every hospital and GP surgeries.
- Before my son attended the hospital, I had to make a call to the hospital to make sure there was a special needs nurse available to support my son. Unfortunately, I was told there was just 1 at Queens Hospital, there used to be 3. This nurse did meet with us and supported my son. Unfortunately, these special needs nurses only work Monday/Friday not the weekends. My son has been in hospital at the weekend and it was very stressful without the support.
- I have had many difficult experiences at A and E in the past namely the new triage queue at reception is horrendous and having injured and ill people queue like they are at a theme ground is unacceptable for a child with autism. A trigger occurred on one visit as one of my children sat and screamed in the foyer and had a panic attack for some time before they could get him a wheelchair (there was nothing wrong with his legs but he was in fight or flight and was refusing to move). This made assessment and treatment after very difficult.
- A green/red card was given for disability or hidden disability for an initial check but after that the waiting room/area was not set up for children who are overwhelmed and the staff had no idea what ASD/ADHD

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was or what form of difficulty this was. The support was non-existent and knowledge was even worse.

- As a carer I have to stay overnight/all day with my person and sometimes the staff then rely on me to do the basic checks. The staff need more training so they can care for people with LD. They also need to look at the person and not relate everything to their disability.

Again thinking about the hospital at which they were an in-patient for the longest time, how well do you think hospital staff were trained in meeting their needs?

- Staff are put under extreme pressure causing them to be at breaking point at most times. This is not fair to anyone especially the trained nursing staff who are continually dealing with high demand patients and having very scarce resources at their disposal. More trained staff required especially in autism related fields.
- They thought my daughter was naughty.
- Waiting in busy spaces is the biggest challenge and cause for anxiety/The support was non-existent and knowledge was even worse.
- The staff also need to read the person's disability passport and listen to the carer.

If they have had more than one hospital admission in the past three years, please let us have comments about their experiences at the different hospitals.

- Queens Hospital was very bad when it came to late night admission for Paediatric patients especially with autism. Doctors and nurses had no clue due to poor training or experience in dealing with autistic children. This could be seen especially with no empathy shown by duty doctor even when he was repeatedly reminded of the needs of the autistic child under their supervision. Parents' input is just completely disregarded causing unnecessary stress to both patients and their care givers.
- Yes, my son had 3 admissions to hospital and he was well supported because I made sure I rang the hospital before he was admitted making sure support would be there.
- Queens Hospital was very overwhelming and frustrating for my daughter and an overall careless experience. King George had more accommodation with space, quietness, efficiency of timings and staff knowledge and patients with children Barking hospital was extremely timely, efficient, and quiet.

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Have they attended a hospital for accident or emergency treatment?

Thinking about the hospital at which they were seen for the accident or emergency, how well do you think hospital staff were trained in meeting their specific needs?

- Some were better trained than others but the doctor was great, understanding and treatment was adjusted because of special needs.
- We came to the Harold Wood Polyclinic when my daughter had a fever. We said that she's been diagnosed with autism and couldn't wait. Receptionist was rude and said all people are waiting. So we were waiting for 3 hours, like everyone else.
- The A&E staff are much better than the regular doctors and nurses as they give regular updates and ask a lot of questions regarding the patient and their requirements.
- There needs to be more awareness of dealing with special needs people.
- A special needs child should not be waiting 6-10 hours for treatment while poorly because it's so stressful when they don't understand and you can't explain and they can't sit still and whining. You keep apologising and explaining to everyone why your child is acting like that etc. why? There

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should be either a section just for them or they are seen as a priority to minimise the suffering and stress for both patient and carer. They are not ordinary people to be treated as such at A&E or GP.

- Taken in for her epilepsy she's also been to A&E for broken bones due to her muscle problem.
- Sensory overload for our daughter, made it difficult to stay and get seen.
- [He] has 22q11 Which hardly anyone knows about.
- Long waits, loud rooms. **Specialist not educated on autism** *[emphasis added].*
- **Despite telling them that he has autism, they never called me out of turn until the child has a meltdown and started beating the wall and chair, which was when they started running around to get him doctor to check him so we can go on time** *[emphasis added].*
- We attended A&E with my autistic daughter during the COVID lock downs. As a result only one parent was allowed to stay with my then 4-year-old daughter. As I was breastfeeding our youngest daughter at the time, I had to keep swapping with my husband to go and sit outside and feed the baby. This caused considerably more distress for my daughter than was necessary having to keep having her parents coming and going into and out of a very busy and distressing waiting area (adult and paediatric A&E all in one place). **There should be increased understanding and awareness that for neurodivergent people (especially children) this situation can be incredibly distressing** *[emphasis added].* There should also be caveats for such situations that the increased infection risk

of having a 6-month-old baby able to sit with her mother and sister in the waiting room is negligible compared to the emotional and mental damage done to the autistic child. The overall wait was substantially longer as we had to wait for a paediatrician with some awareness of neurodivergence to examine my daughter as she was refusing to eat/drink/take medicine orally. Prior to the arrival of the paediatrician with neurodivergent awareness my daughter ended up having a suppository for analgesia. This could have been avoided had the paediatrician examined her sooner.

- We weren't aware of the Hospital Passport scheme at the time and no-one mentioned it. A has been to A&E on several occasions, and is always extremely distressed by the long wait surrounded by people in pain etc. This has also been compounded by being sent to incorrect departments on several occasions despite my advocacy, as a result of his GP not providing any information in advance to the hospital (as we understood she should have) and some staff at the hospital not listening to us. When we had followed up/booked appointments, treatment has been better so perhaps it depends on training being rolled out and different pressures on different departments.
- Main reason because parents make sure it happens and is seen quickly.
- When someone with LD is attending A&E it would help if they were able to access care straight away as some people with LD don’t understand the concept of waiting and it can be very hard for the carers.

Comment

For most people who have a learning disability or autism, a visit to hospital can be incredibly challenging. Whilst acknowledging that hospitals are a busy and stressful environment for most people, staff as well as patients, mitigations are available to reduce the anxiety experienced by people who have a learning disability or autism – and those accompanying them – at little or no cost.

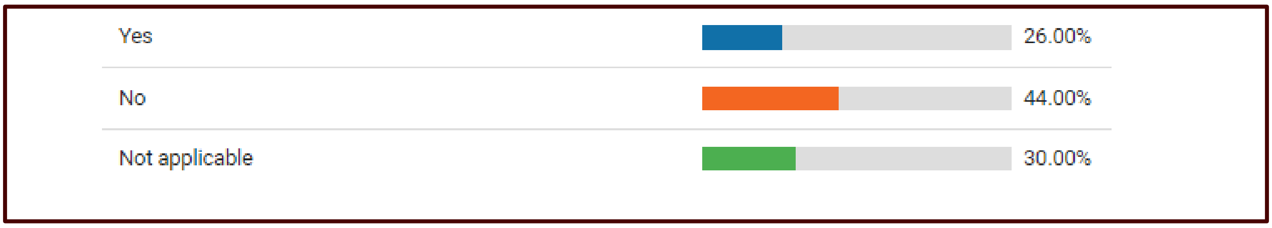
Most hospitals – including Queen's Hospital – have a passport system for people who have a learning disability or autism to enable staff to identify them and provide extra care.

But these mitigations only work if staff are aware of them and have been trained to use them.

The comments from carers who responded to our survey suggest that more needs to be done in this respect.

Theme: Managing challenging behaviours

If you are caring for a person aged 18 or under, and they display challenging behaviours because of their disability or autism, have you received help from services to assist you / the child with managing those behaviours?



- Paediatrics is setting up a meeting with a psychologist for medication to help.
- We don't have challenging behaviour but haven't been offered any help by the council on areas of concern.
- He has been under CAMHS a few times since he was young. Schools and now college are usually helpful and supportive up to a point but because he is academically bright, he could never get EHC plan & therefore was not entitled to extra help.
- We have had help through therapies paid for by the adoption support fund, but the NHS community physio hasn’t really helped and CAMHS have discharged us for not turning up to an appointment we didn’t know about and the appointment was booked for 28th March, not 28th Feb as they said.
- I would say signposting is the norm in my experience, but at the end of the day not a lot of actual help available.
- He receives a personal health care budget but we are unable to find a carer for him due to his complex diagnosis/behaviour so the hours/budget are unused and does not meet his needs.
- CAMHS have tried to help but not been helpful as child won’t engage. Very complex ASD. No other alternative offered. Social Care in Havering are not doing enough. Significant risk of harm to family members and 2 suicide attempts
- Challenging behaviours come from frustration with not being able to communicate. There are no departments, support, or guidance on how to help with this. As a parent I

have taken courses online and familiarised myself with communication cards, trialled a number of strategies that help my daughter to be able to communicate in her own way. I have then delivered this to her mainstream school through her EHCP and 121 meetings. Visual Strategies (5P approach) NAS Website for behaviours that challenge should be distributed out to all schools to ensure the staff are aware of what behaviours look like, this should then be discussed WITH the parents on what strategies and calming solutions can be used to HELP the child. No where in Havering not even CAMHS offer any form of support that is useful for everyday life.

Is that child supported by their school to help manage their challenging behaviours?

If so, how are they supported?

- They understand triggers and also share information on tactics that work.
- A parent/teacher report back system.
- He is seen by a speech and language therapist as well as an OT specialist in sensory issues.

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- In school via EHCP behaviours seen at home are not always seen in school.
- The take strategies and calming mechanisms that are used at home. All are documented in EHCP and I ensure they use a communication booklet.
- She has learning mentors at school who intervene and take necessary actions and provide assistance when things go out of place.
- Was not allocated support as no EHCP, they support her with her emotions, anxiety, and confidence
- They support her with her emotions, anxiety, and confidence.
- School have managed to curb his behaviour at school.
- He has one -to- one support in school throughout the day.
- He is in a SEN college; the staff are excellent but he struggles to fit in.
- 1-2-1 support from a TA (however they are not SEN trained and the person with him has changed several times which has caused issues with him not wanting to go to school and with his behaviour).
- He has only just started a new school after being out of school for 3 years, so it’s hard to tell if the strategies that they are using are helpful.
- Receives 1-2-1 support in school which provides emotional support throughout the day. Following private assessment my twin boys are now receiving OT via their EHCP (huge gap) which includes sensory support. This has greatly improved their behaviour on journeys home and outbursts after school.

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- Not in education. No suitable school been found by Havering.
- Form tutor & Sen at Brittons Academy have been great - after school clubs been really helpful for friendships.
- They support when he is there but no support for when at home.
- By her EHCP and each term focusing on small tasks to achieve i.e. visuals Makaton for emotions, needs and wants 1-2-1/IEP meetings focusing on what she needs daily to help regulate in school and what her behaviour means to her. Communication daily.

Comment

Challenging behaviour is often born of frustration – difficulty in communication is probably the leading cause. And manifests itself differently depending on the settings in which the person is at the time.

The general difficulty in accessing non-crisis mental health support is an area that needs to be examined more closely but that is outside the scope of this report.

Advice for parents seems to be hard to come by – please see the Comment following the next theme.

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Theme: Availability of information and support

To support the person you care for, can you easily access information on health and social services and support for people with a learning disability or who have autism available in your local area?

- I am reliant on other SEND parents for information advice and support.
- I was trying to book a DABD service for 2 months, people just ignored me, didn't respond.
- Everyone and everybody are providing very generic help. As Autism is a spectrum no two children are the same or have similar issues. The care and help needs to be specially tailored to the individual child. This needs more funding from the local government and channelled through to the children and their families to support them better. More input is needed from the different support organisations and specialists.
- Services and support need to be better signposted.
- As a parent of a disabled/severe learning disability young adult, information is hard to come by and you learn more from other parents who are in the same situation.
- There is very little support for age 5 to 8.
- I self-research and use a lot of FB pages SEN COFFEE group being the best one. Other recommendations and experiences…. all services in Havering have long waiting lists so I learn online programmes to help my daughter at

home. There's no seamless journey for parents to seek help training or support so we use each other to fight the services that our children are entitled but are often too late so we have to self-teach.

- No one tells you what to do or where to go or who to contact. You have to figure things out yourself or coincidentally stumble upon them. Some require an annual fee which should be free in such hard times. Why is there no system that children with suspected autism or a learning difficulty is automatically directed along with his carers to those organisations and services via GPs, the Acorn Centre, school and or social worker for example. Makes life a million times easier, more organised, and less stressful.
- School is failing my child's development and refused access to educational psychologist for assessment
- No proactive support. It is up to parents to remind and book appointments. Issues with referrals especially with hearing as this is an ongoing issue he has to constantly be re-referred as BHR will not keep him on their case load. Parents/carers and the individual have to constantly go to the GP which means that this is an unnecessary appointment which could be avoided if he was retained by BHR. No ongoing and proactive support from Social Services although reviews are necessary.
- There is no clear pathway for Autistic people In Havering. We were 'lucky' to find First Step Opportunity Group when he was 3yrs old - they provided great assistance in obtaining guidance and a specialist paediatric consultant.

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- I have a good network to approach for information on how to get support.
- Much of the information I have been given has been from the local Havering Autism Hub, which I contacted myself after passing the office whilst in Romford. I was not given this information by any other professional, but to be fair, my niece is currently awaiting her ADOS assessment. Her local health clinic did not give any information about local support that might be available for my niece, and I think that we might have accessed information sooner, had we known where to look when we originally raised concerns about my niece's developmental issues.
- There is no support. Either for him or myself. CAMHS is for a short-term therapy. Each time there is a problem you have to visit the GP and ask for a referral then wait for a very long time on the waiting list.
- Information needs to be more accessible. CAMHS needs an overhaul as one appointment I went to without my daughter left me feeling like a bad parent. Understanding of developmental trauma, attachment needs, and how this impacts brain development
- The services in this borough are very hard to access and unheard of. It really is dependent on who you know and who you talk to, to make that initial contact. Once you have made contact you are then constantly chasing to try and make something of it. And if by some miracle you have managed to speak to someone then there is usually a massive waiting list or what you are offered is not sufficient because the help you get doesn't matter how challenging the child is but dependent on if you're on benefits or a

single parent. For us working parents there is no support. I have had to take unpaid leave over the summer so that I can look after my child. Not to mention that just because I work, I am at a disadvantage in accessing help and because we are a nuclear family. Despite my husband working full time I am not entitled to any support. Even if suggestions are made to improve services it will be hard to see an improvement as barely anyone can access these services. Each family in Havering with a special needs child should have access to a family support worker or a contact from the council. Each child should be seen by a GP to carry out regular health checks. Especially if the child is non-verbal and is scared of visiting doctors and dentists. Why are they scared they have not had exposure or have not had the chance to build a rapport with the health care professional. There is so much that needs to be addressed but difficult to say all. One thing that is apparent is despite paying taxes it seems we are less entitled than those who live off state benefits! Do something about this! Everyone should have equal access or to at least a baseline.

- We have been on the waiting list for a social worker since January.
- Needs to be more SEN information available on council websites, medical settings.
- Directed to CAD team online and given 100 hours for outing for one year. But the problem is the facility that can be accessed through it does not provide enough days for activities. For instance during the six weeks holidays, you can only access the facility just for 3 outings for one child as there is no adequate provision to add additional days.

- I am aware of the Havering "local offer" but when you look at the information on line it is very lacking. No information regarding what the guidelines are (i.e. annual health checks). No list of local medical/dental services that are autism aware. The information provided at diagnosis by the medical services is very scanty and verbally we were told to connect with other parents as the best way to find out about things. This advice should be taken in the context that many autistic children also have family members of a similar neurotype, so the advice to "connect with other parents" may not be an easy task for many parents/carers
- Personally, I am pro-active and over the years have found where to go/where to look for help through my own endeavours. A lot of the time this comes from other parents / groups set up/run by other parents. I can see that it may not be possible for everybody to do this.
- It’s up to you to ring around and find out what’s available. It’s time consuming and you are reliant on the person’s knowledge and experience that you speak to.
- I have found it difficult to access services and support for my child. The Sycamore Trust have been a very good resource for help and advice, however other services are difficult to find out about. The waiting times for appointments have been extremely long and there have been some traits ignored by certain services. The child’s autism was ignored by the first paediatrician. It has been very difficult getting my child the support he needs in school. The constant change in TAs has affected his behaviour and has led to him not wanting to go to school. None of the TAs have SEN training. They received in-house

training from the SENCO who told me TAs cannot go on SEN training courses.

- No information, it’s like trying to find a needle in a haystack.
- I have asked his CLDT for support about various things but they either can't or won't respond with any reliability - it depends so much on who you happen to get. For example, we had a visit from someone brilliant a year or two ago, who organised so much help for Anthony (stairlift, new path suitable for his wheelchair etc) seemingly very easily, whereas aside from this one social worker, the others have been extremely difficult to get hold of, and, frankly, not very helpful. For example, aside from asking for counselling (see above) I have asked for advice on how we might help A get out and about more socially, but we have not heard anything back about this. We also spent weeks trying to sort out transport for his day centre once his disabilities made it too difficult to use their usual bus transport, and again, it was like pulling teeth to find a solution. However, when they need some service user feedback, I am asked to give this within a number of days (and I tend to, although I don't get that myself). I would love for A to have a reliable, named Social Worker who actively contacts him/ me regularly to find out how they can help, or at the very least respond to calls and emails. With this not seeming to be possible, it would help me a lot to at least know why not (e.g. what other pressures they are under) as you can't help but feel you don't matter and any contact is a nuisance or not even being considered. I can imagine they are under pressure with the Tory government/cuts etc but I am completely in the dark. I think people with LD and autism deserve better - at the bare minimum, carers

should receive responses to communication and ideally there should be more pro-active help.

- But there isn't anything for autistic teens with no learning needs who have PDA ADHD and behaviour that is challenging. No support for parents.
- Difficult to get help when undiagnosed ASD parent finds communication difficult.
- My adult child and I have not been able to find any autism organisation that can help her. We contacted the Autism Hub in Romford. We were informed that they do not provide support/ activity groups for adults over the age of 30, they only can only help a younger age range. If she wanted to join one their groups. she had to as a volunteer. She would not be allowed to participate in any of their groups/activities because she is over 25. She declined their suggestion. She just wanted to receive some support, not be one giving support to others.
- Yes, they can be accessed easily via the Havering family services hub, but everything is referral or appointment with extreme waiting times. There isn't any guidance or training recommendations or courses available for parents to help their child to help the school. FB Pages are a wealth of knowledge from parents who have experience but no parent forum set up by Havering just yet to have a base for parents to reach out and have 1 point of reference to help their child.
- It is easy for me because I know how to access the services having been in the system for so long. The thing I find really frustrating is my GP is still not offering face to face appointments only telephone appointments.

Comment

This theme – and this specific question – attracted more comments than any other in our surveys, indicating that access to information about support services is the key issue for carers and its lack is the main reason for dissatisfaction.

As one comment says:

"it's like trying to find a needle in a haystack"

Some people seem to be able to find information but clearly others cannot. Thought needs to be given to how people can be helped to find information when they need it in an easily understandable format.

In this connection, although information is available through the internet, it must be kept firmly in mind that not everyone can access the internet or has the time to "surf" it in search of information [4] .

Consideration could perhaps be given on a cross-agency basis for the appointment of a dedicated caseworker as a single point of access. Moreover, local organisations such as First Step and the Havering Autism Hub, both of which were founded by parent/carers themselves, may be able to help.

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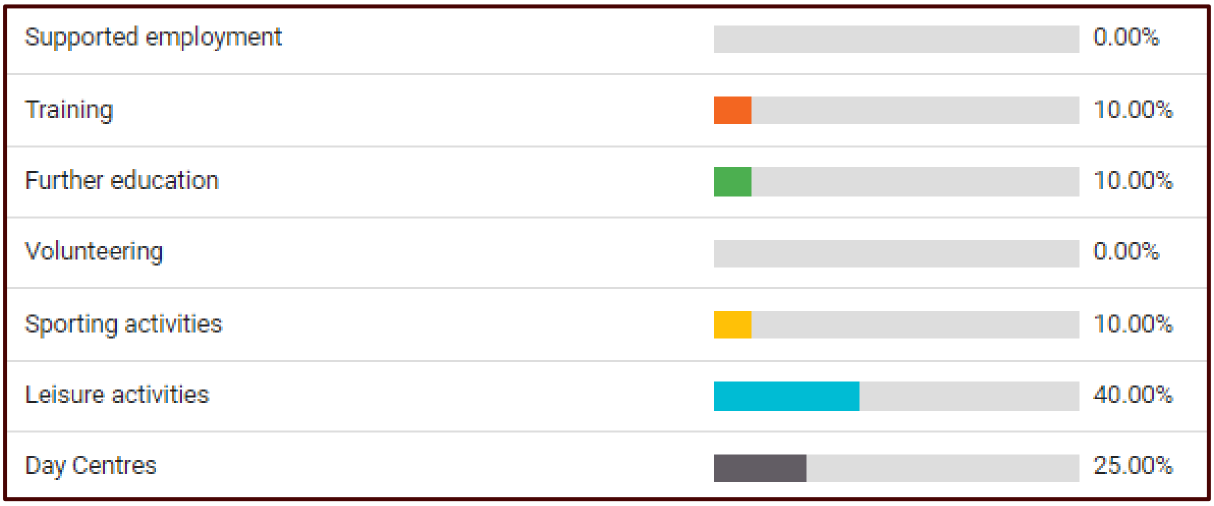
[4] That said, good information is available from this website: https://www.autism.org.uk/advice-and-guidance/topics/communication/communication-tools/visual-supports

Theme: Employment, training and social activity

Does the person you care for access day opportunities (for example employment, training, and social activities)?

Yes	35.56%
No	64.44%

What services do they access?



Supported employment	0.00%
Training	10.00%
Further education	10.00%
Volunteering	0.00%
Sporting activities	10.00%
Leisure activities	40.00%
Day Centres	25.00%

- Only opportunity was one which parents found. No support from Social Services regarding this and once they were informed the process was not made easy.
- He attends Education for Independence which is part of Havering Adult College which is an excellent resource for Havering Special Needs/Autistic people although there is no specialist service available. It provides a service for all Learning Disabled people.
- Day opportunities are good. They could be more widely publicised.

- My niece is 3 years old and has been able to attend a local nursery part-time, however, she had to move from an earlier placement as they were not able to support her needs; her current placement is in a smaller setting with higher staff levels, where they do their best, but have no professional help and advice to help them care for her particular needs.
- We have tried to encourage him to participate in social activities but as yet none can meet his needs.
- A goes to a day centre, which he loves, from 10-3 on three days a week. He really appreciates doing different activities and meeting different people and it gives him a sense of purpose (he calls it 'work'!) He would like more stimulation - e.g. social evenings or leisure activities - and while we do all we can as a family, he'd love some different people to go out with occasionally, but I'm not sure how to find someone to help and the CLDT haven't responded to me asking about this. I intend to continue asking around to see if we can work something out ourselves.
- There are no social activities apart from the ones that are organised by parents on FB groups for SEN sessions - Family information Group (FIG) [5] which is 1 day every half term.
- My daughter’s day service is very good. Although it would be nicer if it was a longer day i.e. 9 to 4 instead of 10 to 3.

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[5] Family Information Group - website: https://familyserviceshub.havering.gov.uk/kb5/havering/directory/service.page?id=cLjc6t2CR3U

Has access to post-school opportunities for people with a learning disability changed (positively or negatively) in the last 3 years? If so, how?

- There has been no positive change, in fact the opportunities have regressed. Total lack of opportunities for the LD/A people to volunteer or work.
- I think places are becoming more aware of inclusivity, and trying to offer opportunities for those with SEN, but as per my comment in the next box, they are not prepared to earmark any primetime for this category (obviously will be a financial loss for them).
- I'm not sure. A is lucky as he has a day centre that he absolutely loves going to (TLC) and the change in his mood when he gets to go is amazing.
- Positive improvement for us. We are lucky that we get 5 days. I do know that young people now won't get a five-day service.

Can you tell us one thing you would change about post-school opportunities for people with a learning disability or autism?

- Need more funding for sure even though I have not used the services. But from experience anything to do with Autism is always way under-funded budget wise. This causes unnecessary hardship for the autistic individuals and their families.

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- More funding for every place to make the experience more enjoyable. Most places are struggling to provide a variety for people with disabilities.
- People with learning difficulties or difficulties come at different levels some high functioning and some struggling to function. They should be taught at school to understand their situation and their strengths and weaknesses. Trained on how to cope with society and how to react in social situations, how to regulate their feelings and what to do if they can’t etc. How to plan and how to be independent, if possible, etc. All this should start from Nursery and primary school not when they are already adults. This will enable them to blend in better with society and develop in a safer, supported, confident and strong environment.
- Opportunities for those able to undertake volunteering opportunities which could lead to being able to work.
- More education opportunities that are free when they reach the age of 20.
- Advertise them better. Have increased number of spaces. Offer different opportunities according to the needs of the young person by describing the suitability of the session for each child. This could be done by indicating the level of support required, i.e. "this session is aimed at children, young people who are non-speaking or those with very severe sensory sensitivities" or "this session is aimed at young people who are speaking and socialise independently but have challenges forming new friendships".
- Some places run SEN sessions but they are usually far too early in the morning or too late in the evening.

Did/does the person you care for attend a training, further education, or higher education course?

- Education for Independence part of Havering Adult College. So much more could be made of this facility - volunteering opportunities etc. Students could then maximise on their potential rather than being on benefits
- He left school last year and went to the SEN unit at the local college. He is doing a life skills type course, there is not much opportunity to study a specific area of interest unless they are able to access mainstream college with low level of supportm
- No support given at college, absolutely rubbish college. Utter disappointment.

Did/does the person you care for receive support to get a job or stay in work?

- A has tried occasional supported work experience in the past prior to his physical condition deteriorating, but his learning and physical disabilities (especially the latter, which have been more challenging over the years) mean he cannot work

If the person you care for attends training, further education, or higher education course, or is in work or looking for work, does he/she have accessible transport?

- Elderly father takes him to and from college owing to the fact that the main stream college comes out at the same time as E4I and because of the vulnerability the risk of harm is too great. Previously at different location and he travelled independently. He has to be driven to college as he can’t stand buses due to people noise & germs. He feels awkward having to talk to a cab driver but anxious if he doesn’t speak, so he refuses. He currently feels he wouldn’t cope with driving himself. He has a poor sense of danger with traffic and so a scooter or bike would also not be very safe.
- I take her by public transport as she can’t and won’t travel alone or with strangers.
- My son will be attending Avelon. He is physically disabled in a wheelchair and also has intellectual disability. More needs to be thought about in relation to physical disability.
- I receive fuel reimbursement and take him myself.
- He drives his own car.
- We had a NIGHTMARE getting transport to A's day centre. His day centre offer transport, but it isn't wheelchair accessible. The local authority accessible transport option is (we were told) £75 - I can't remember if that was each way or return but either way, for 3 return journeys it clearly isn't affordable at all. His Taxicard offers 100 trips per year, which are used up very quickly with 6 trips a week to his centre, and they also need to cover medical and social appointments, so we need to find transport for the

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remaining many months of the year. We had to find our own transport (accessible private taxi drivers) to A's day centre, and negotiate payment with the LA through the CLDT, which took weeks but is now relatively stable. The local authority accessible transport offer should be far more reasonably priced - it is ridiculous. We had other things suggested (e.g. Dial A Ride) by various agencies and forums, but they DO NOT work - they won't do trips to day centres and are unreliable - and yet EVERYONE suggested them, it was infuriating! We even had to work with national advocacy organisations at one stage to get any response from the CLDT. Transport for LD and autistic people comes up regularly on internet advice forums too - you have to work so hard to get it and it is a legal right. Like everything else, SO frustrating and time-wasting.

Did/does the person you care for attend any other training locally (e.g. through a community / voluntary organisation)?

- Training is offered in a local cafe supported by charity (Unity Works). Aim is for the individual to move on into employment, although no employment is ultimately available for those with these specific needs.
- We joined a charity, who run events like football & group trips but these don’t suit him.
- He has accessed a Sycamore Trust group which combines life skills with social opportunities.

Comment

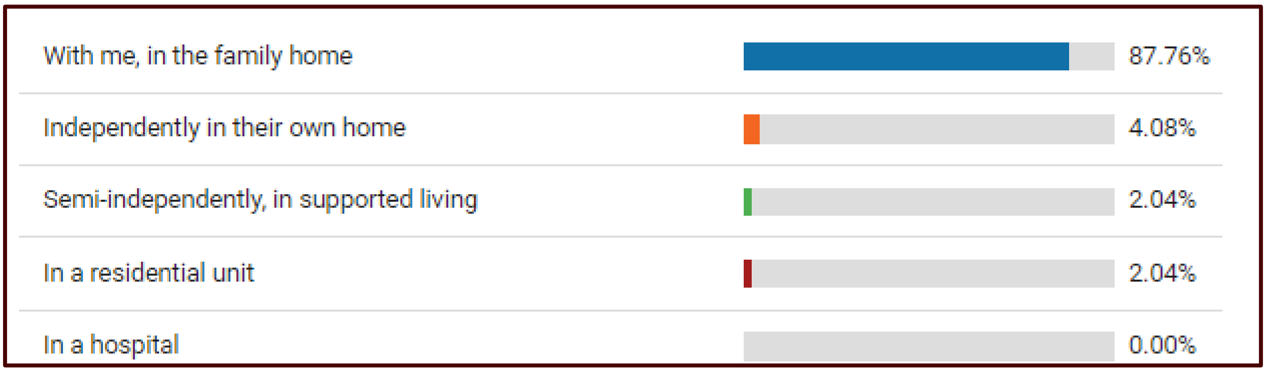
The freedom to go out and about is a basic human right but many people living with a learning disability or autism are unable to experience it. For some, environmental factors over which they have no control – noise, crowds, dogs – are a deterrent but for others, transport to and fro is a major issue, despite the availability of schemes such as the Freedom Pass and Taxicard.

Training opportunities are not always available.

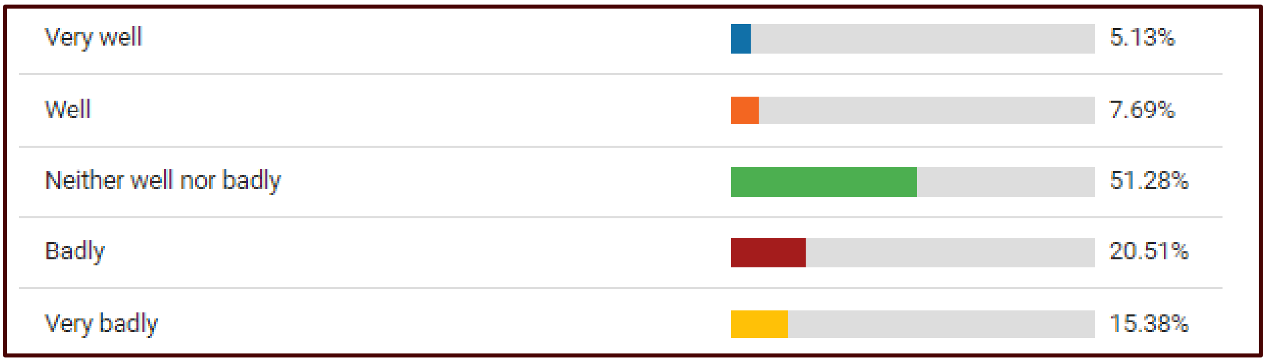
Previous responses in this report have pointed to the desire of many people with learning disability or autism to be employed in a suitable environment. The avoidable barriers to people living with a learning disability or autism being able to enjoy freedom of movement or taking up suitable employment need to be addressed and, where possible, eradicated.

Theme: Living in the community

Where does the person you care for live?



How well do you feel the person you are caring for is supported to live in the community?



- Again the individual is forgotten about until something serious happens to the individual. No forward planning or forethought is given to the person living with autism within the community unless serious issues arise.
- Other than school, access to clubs has been difficult but HAF project has helped a lot. After school clubs need to be supported to put on extra staff so additional needs children can attend just like school.
- My son has been left without support and education since October, the Local Authority has totally failed him. They haven't put anything in place for him.
- Bullying at school rips apart their self-esteem making them even more unable to socialise and adding mental health problems to the equation. There has to be extensive awareness starting from primary school on learning disabilities, autism, ADHD and mental health so the children understand it and grow up supporting it and handling it with care and compassion.
- The scheme has been taken over by L&Q and the standard and hours have dropped. There has been an issue with

staffing and a lot of Agency is being used causing issues with consistency.

- No overnight respite centres in Havering for the physically disabled who require specialist equipment i.e. beds, hoists etc. No daycare centres either at reasonable times after school.
- She is supported very well by us (her two parents), her grandparents and staff at her school.
- We were allocated a social worker when he was 16 but she changed jobs and we have had no further input.
- Accesses mobile support from Peabody.
- My sons receive an EHCP and are supported in school. After school services and holiday club access are virtually non-existent. I had to give up my job when my children started school despite being able to make it work whilst at nursery. (Longer hours in private nursery).
- Things the person we are caring for feel supported include his day centre, the brief but effective support we got with things like the stairlift from the CLDT, and otherwise local buses, pubs, restaurants and bowling being wheelchair accessible and the local leisure centre offering fitness sessions for people with learning disabilities. We'd also. love to join the swimming sessions locally but they are on days A is at his day centre and he refuses to go during public swimming times as it frightens him - he likes the quieter disabled sessions. All these things help A feel part of the community, if not exactly 'supported' per se. We'd love A to feel more part of the community with more independent social options, as otherwise his social life is almost all with his family. Disability legislation and health advocacy

groups such as yourselves help people like us enormously by keeping the rights of people with LD and autism on the agenda. Thank you!

- I am his only support. No one else does anything for him.
- She has never received any support since diagnosis 2 years ago.
- There isn’t anything in the community for my daughter to use to be cared for.

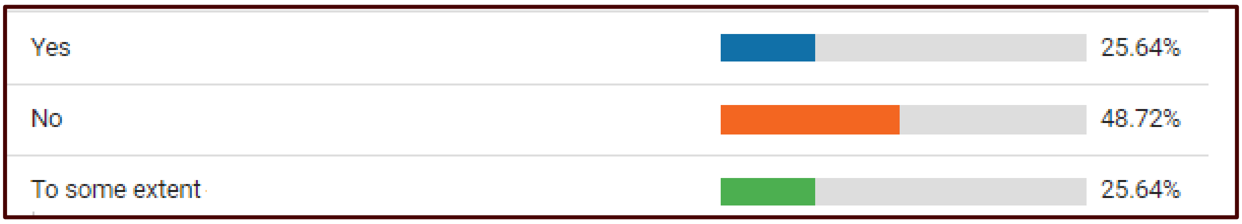
Comment

The feedback again highlights the lack of useful information or, at least difficulty accessing it; it Is available because some carers have been able to access it.

The feedback also highlights the problems people experience in being heard or obtaining the support they need.

Theme: Meeting accommodation needs

Do you feel that the person you care for has had a choice about where, and with whom, they live?



Do you feel that the place where the person you care for lives is suitable for them?

- We had to adapt the house our child lives in with our own money. We are very fortunate in being able to carry this out. However, there are many thousands of people who will NOT be able to do this for their child and hence their child will suffer through no fault of them except lack of funds.
- House not suitable but not allowed adaptations to make it suitable as we're applying for residential care but been rejected for 2 years due to challenging behaviours.
- Havering Council is known to be one of the worst boroughs in London for their lack of care or empathy, assessment, assistance or anything to say the least. My child requires a garden or a close by garden or park for her outlets ADHD+ Autism. She also requires stability. We have been moved by the council 4 times in 5 years! Mostly in flats that are not suited to her needs and in neighbourhoods that pose a threat to her safety! Never have we been assessed by the council to see if the accommodation we are being moved to is suitable because they have a housing problem and as they say we should be grateful we are provided with a roof over our heads!! Yup… we have to accept it and suck it up sadly.
- Information regarding living elsewhere is not easily accessed - there is no real person to liaise with just Social Services and that is difficult in itself.

- Living arrangements are highly suitable - a bungalow in a small community specifically designed for those with learning difficulties. The place is monitored by the Peabody group who check in on residents.
- It’s her home, her safe place where she feels happy.
- Yes, it’s our family home but we as parents need our own space and we are not getting any younger.
- At the moment. He will require full 24/7 care in a fully supported home if we cannot cope in the future.
- He needs a place he can play at home and a room too but due to the housing issue problem, we both share a bed and he is very hyper and has sleep disruption. All these affect my sleep and I can hardly sleep for 6 hours in the night. The house has no space and no garden to play, this resulted in damaging things in the house in the process of playing.
- Would have liked more choice in the areas on offer. Also he is housed in an area with a lot of people with mental health and anti-social behaviour issues which is frightening.
- A is currently in the family home that he has spent decades/almost his whole life in, with family members caring for him full time, and he loves it here. It is familiar to him, it has been adapted to suit his disabilities and is relatively close to his day centre, bowling and parks and pubs he likes to visit. However, it is a council property and following his mum's passing, his future is insecure and he will have little choice if and when he is forced to move. If he had 'just' LD we'd love to find/support him in a positive, independent living group setting, but his physical disabilities make it extremely difficult for him to move

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safely and independently (and sadly all you hear about care settings in the news is how terrible they are, so I couldn't bear it!) I therefore feel we have to look after him personally as a family so we can be sure he is safe and happy, which is our top priority. I'd love for all people living with LD and autism to be able to live wherever and with whoever they like but it doesn't seem like this is realistic, at least for A with both complex physical and LD, in the current climate.

- I was told that she has no option but to live with me. If she was able to live in her own place and receive a little bit of support, she would not be allowed to apply for housing. The council would deem her to be priority despite her mental health issues and having autism. So she would have to still continue living with me indefinitely.
- As she gets older and I get older, she will need to access residential accommodation. There are not enough services within Havering for this and will most definitely have to move out of borough possibly more than 2 hours away

Comment

It is distressing to read that someone feels the need to move away from the borough because they perceive that there is a lack of available services to meet the needs of the person they care for.

Equally, for Havering to be described as "*one of the worst boroughs in London for their lack of care or empathy, assessment, assistance or anything to say the least*" must surely be a wake-up call for the health and social care sector as a whole.

Theme: Developing services for people living with autism or learning disability

Have you been involved in helping to develop services for people with a learning disability or autism in your area?

- I run an Autism Singalong Group in Harold Hill Library. [6]
- I have tried to volunteer but my services were never taken up.

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[6] Go to: https://www.havering.gov.uk/events/event/2771/autism_singalong_fun_club

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- I was asked to but didn't hear anymore after the initial invite.
- I'm trying to set up a patent forum for Havering which is taking a considerably long time.
- No clue where to do that.
- I have volunteered to be a patient carer representative at the Acorn Centre and reviewed a letter template that they send out to parents. Language used was originally very ableist and blameful. I was also asked to present to staff at a staff meeting, but only given 1 day notice. As a result I was unable to take time off from work to attend. So far that is all they have requested from me.
- I work full time from home as well as looking after A - I do all my meetings while he is at his day centre, and often do my paid work early morning and late evening around his needs, so I have no time at all for anything else, much as I'd love to be involved in something like this that I know A would also benefit from
- I sit on the LD and Autism working group at Queens Hospital. I’m also a member of the Partnership Board

Comment

For those who have the time - and the passion – to help develop services for those living with autism and learning disability, there are clearly opportunities to get involved.

While it may be difficult to do so, more encouragement should be offered to others to participate even if only occasionally.

Theme: Your experience as a carer: finance

Have you been offered a carer’s assessment to help identify what support you might need with your caring role? (A carer’s assessment is a review of your caring role and how these impacts on your life, to identify if you require support; it will usually (but not always) be done by a social worker)

If you answered yes to the last question, did you accept the offer of a carer’s assessment?

- My child received the 100 hours package and some FIG allocation.
- This was done 3 years ago due to my own efforts and nothing else has been done thereafter.
- A complete waste of time!!
- This assessment was done many years ago when we were working; we are now OAPs!!!! The offer made then is still in place today even though we are that much older.
- If offered, I would have welcomed this. I enquired to Havering 5-19 CAD team about obtaining a "carer's card" to

prove my role as my daughter's carer when we attend days out etc. This is something offered by other Local Authorities (e.g. Newham) and they were unable to help me with this at all and had never heard of it as an option. They recommend I pay for one from a third party (that required no proof). I do not think such a business is ethical, so did not do this.

- When my son had a social worker, I asked for an assessment several times. This was also meant to be actioned as part of his CTER plan. However this was never carried out and has since been discharged from social care.
- I am actually not sure about this, I may have had one and forgotten, but either way I can't imagine anything useful coming from it I'm afraid. I should add that my sisters also help care for A and our main concerns are his health and happiness. While I have developed a chronic, stress-related condition (Graves disease) partly, I'd imagine, in response to bereavement alongside trying to juggle caring with working full time, I think looking after him ourselves is the best way to ensure his health.
- Would have loved this - no idea how to go about it
- I have had one carers assessment over 20 years ago and was not offered any help.
- FIG is oversubscribed and not as effective as it used to be for my child with his age. The 100 hours are used fortnightly (monthly during summer holidays) but options for trips are still limited as the child does not like to leave the house.

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- This should be reviewed regularly/if the LD/A person was to go into residential/ independent living it would cost so very much more than him living with us.
- My son is worried about what will happen when I die so we are working with Peabody that he uses them as a first point of contact.

How satisfied are you with the support - if any - you have been offered because of that assessment?

- There's no support for working parents. No after school clubs, no holiday camps. Nothing.
- I have had no overnight respite for 4 years. Allocated nights, but social care say there are no suitable places.
- Carers assessments need to be looked at regularly- age and health being two main factors which impact carers who still have the same responsibilities of their disabled person as they did from birth!!!
- I was told if I was a single mum, I would have got more support. If anything they gave me less than 100 hours that he could have got without the assessment. Waste of time and effort could have just told me from the start that I won't get anything because I'm not on any benefits and I'm not a single unemployed mum.
- My son is very able in some areas and I think this is reflected in the fact that no one thinks that my role in his life requires assistance especially as I work with children with special needs.

- Lack of communication and disappointed with how slow the service is at putting things in place.

Have you received direct payments to assist you with your caring role?

- It's troublesome trying to organise competent respite workers whose schedule can match ours.
- So hard to obtain direct payments, I had a battle.
- Process was difficult I felt staff were not trained appropriately doing the assessments.
- Direct Payments has always been efficient except this current year - been waiting since October 2022 for it to be resolved.
- Given me a chance to rest and get other things done and build up my own resilience in addition to my daughter doing activities to develop herself
- We have a carer who takes him out occasionally also BOSP sometimes.
- The main problem is finding carers to carry out this role, it's a very common problem that affects many parents/carers.
- My son uses direct payments to go to various activities e.g. bowling, swimming, golf. However. I do not get a break from my caring responsibilities as I have to go with him and also take part.
- See above. I've been discussing already Wrap around Care via holiday and afterschool clubs that's support higher care ratios and holidays or days out.

- I think A gets 'direct payments' but we use them to cover his three days at his day centre - perhaps that's connected?
- I have in the past when my daughter was social care funded. Do not have them now as my daughter is CHC funded.

If you have received a direct payment, please tell us how that has helped you to meet the care needs of the person your care for, or to support your caring role.

- It gets him out of the house for short periods in term time and has longer lengths of time allotted during school holidays.
- We use the help to improve our son's life as best we can. By taking him on holidays and days out locally and internationally.
- Direct payments have only been able to provide 5 hours respite in the home per week. Definitely not enough.
- DP has been difficult to access I now use DP to pay for extra support so my children can attend clubs.
- I'm able to attend appointments without my daughter.
- My son only gets 6 hours a week which is not a lot.
- It has helped with transportation and signing her up for swimming classes and drumming classes and with specialist books online etc.
- Direct Payments pay for [his] college fees and respite.

- So that I am just able to afford to be at home to take care of him.
- It has meant a PA could take her to things she likes to do that if I took her to would be too stressful for me.
- It enables you to pay someone to take your child/young person out, giving them some time away from home independently and giving the parent/carer a break.
- It keeps my son active and allows him to participate in activities which would normally put a strain on the family's finances.
- Respite care for a few hours each month.

Do you receive a Carers Allowance? If not, why not?

- I work over the hours.
- I earn £23 more a week than the threshold, it's a disgrace.
- Didn't think I could claim anything.
- It's means tested and I'm not eligible for this
- Currently on low rate for hypermobility and Ehlers Danlos syndrome waiting new assessment for ADHD, DCD diagnosed last year.
- I work (two respondents).
- Because I work and earn slightly over the threshold.
- I looked into it and it's apparently just under £70 a week, which would be impossible to live on. I would love to know who does manage to live on this and how. I am, in a way, fortunate that I can work from home which allows me to combine work with caring. Otherwise I would have to have

resigned and I have no idea how I'd manage on £70 a week.

- I was told it would reduce the money he got.
- No idea how to do it.
- Do not meet the criteria.
- do not meet the threshold.
- Because I get my state pension. I've not stopped being a carer just because I turned 66 and I think it's disgusting that I'm no longer able to claim carers allowance.

Have you had a benefit entitlement check to ensure you are receiving all the benefits to which you may be entitled?

- We earn too much and aren't entitled to most benefits.
- No idea who offers this.
- Don't know how to apply.
- Never been mentioned or offered.
- I know we're not as we both work.
- Krone contacts parents with help or support we inly contact LBH if there's a problem.
- Carer's Allowance and DLA are all that's available as I am aware.
- We know what we are entitled to her dad works as well so we understand what help we can get.

- Nobody has offered us one. I have independently applied for DLA for my daughter and she is receiving the caring part of the allowance. Owing to my income I know from the information available on gov.uk that I am not eligible for carer's allowance.
- I am working full time so I don't qualify for any benefits. A receives ESA and PIP so his needs are mostly covered, with help from family.
- Not heard of a benefit check.

Comment

The financial circumstances of many informal carers are clearly difficult – for those in employment, juggling work with responsibilities at home is very difficult; for those who are in effect full time carers financial support is clearly hard to come by.

State financial support for carers is outside the scope of this report but, from what these respondents have told us, they face an uphill struggle to get the finance they need.

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Theme: Your experience as a carer: other support

Have you received any other support to assist you with your caring role?

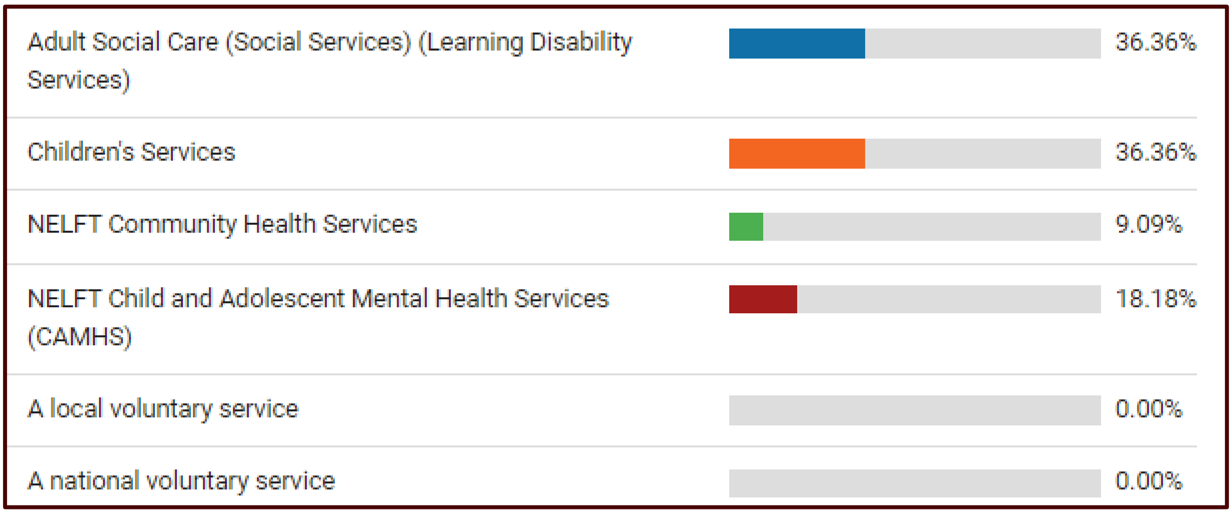
- We get DWP help mobility and care elements both at high rate.
- Via children's EHCP I access HAF funding.
- Nothing - no-one asked us as a family how we might look after A following his mum (and main carer's) death, and while we are fine to be left to it, it would have been lovely if Anthony had any care/continuity of care from a named and dedicated social worker. I dread to think what happens to people in his position without family members able to care for them. I found places like Havering Carers' Hub but they seem more like places people looking after partners or parents with dementia might find support from, and there are sites like Sibs but again, I've not really felt like they offer the kind of specific advice and help we might need. But we are doing OK and, in a way, we'd rather do what we are doing and be left alone in a way!
- Carers have been put in place from a care company.
- I would like to see sensory training for all schools, parents and professionals. It’s vastly misunderstood and could change the outlook for many students in mainstream schools in particular.
- No/none at all.

Have you been offered help to plan for the caring requirements of the person you care for?

- No concrete planning is in place as yet.
- They aren’t interested.
- EHCP at school? Unless you mean something else then the answer is no.
- Only in respect of my daughter's annual review. Ensuring that her needs are met.
- This is of great concern and we have received no information regarding this at all. Although my daughter is still very young (5 years old) this is a worry for us as a family right now. Services should not expect people to not be concerned for the future just because it is a way off.
- I image this would be something the social worker might do.
- This would be greatly appreciated.
- While my mum was very unwell, a trainee at the CLDT sent us an excel spreadsheet of potential 'care home' type places. It was not very inspiring and we couldn't see anything that looked positive and might support A's specific combination of needs, sadly. Our own research (Internet searches etc) has also not turned up anything very inspiring, including specialist (e.g. Mencap) forums, which is disheartening.

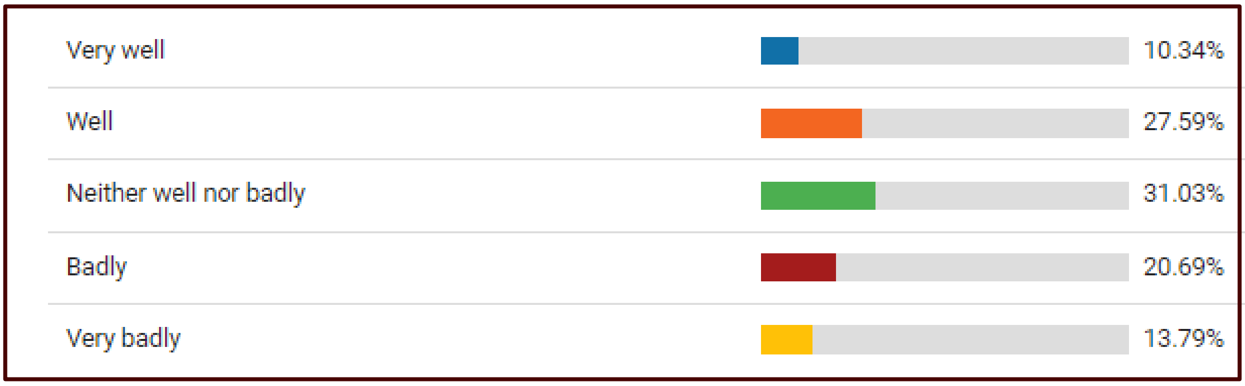
- I'm in process to plan for my daughter's future for when I'm no longer around. I have not been given any help.

Who offered the help with planning for the future



- No idea how to access the above support services without a referral.
- We are currently being seen by the Acorn Centre for ongoing assessment/medication reviews.
- Despite setting up systems such as asking to be contacted first at my son's request this just doesn't happen. Only when I complain it improves for a short while. What is the point of doing this if nobody bothers to read his notes.
- Services are very disjointed and do not actively share information.

Thinking about the professionals who have offered help, how well do you think they were trained in meeting their specific needs?



- More help is needed in this area.
- The support is hugely reliant on government funding which keeps getting cut and is not enough this support and services are limited and not up to the level required.
- Not enough known about acquired brain injuries
- My son was identified with problems from a young age, but got 'lost' in the system, I had to pursue a lot of avenues myself, resulting in a diagnosis around the age of 8/9, then two further diagnoses much later on which were done after professionals raised concerns during routine checkups.
- Peabody have always been extremely helpful.
- You need to stop blaming parents and sending them on parent courses when they ask for help. All this does is make parents think that they are not good enough and they stop asking for help which is much needed. The parenting courses have a low success rate as it is not tailored for SEND families and is a waste of public funds. It’s not a parenting issue, it is a lack of services for SEND-families issue.

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- As mentioned, the most they were able to offer was a spreadsheet. We did not feel reassured, from the descriptions given, that anywhere would be a suitable place for A.
- A paediatrician at the Acorn Centre asked me 'How did you get your daughter to speak' as she was non-verbal until 4 years old.

Comment

Again this service is very muddled. Someone quotes "services are very disjointed and do not actively share information", which just about sums it up. Positively - Peabody are quoted as being extremely helpful.

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3 Professionals

Theme: Your personal experience

How do you feel about your work?

- I love being with my students and helping them achieve things they didn't think they could do.
- We support and prepare autistic job seekers for work. The job is fulfilling and we see the outcomes of our hard work when our clients and learners achieve their goals.
- I have a lot of support from my manager and colleagues in supporting children and young adults who are adopted, many of whom also have learning disabilities or diagnoses of autism.
- I believe that we provide high quality personalised care and support.
- I have a job that helps me to support families in the community, to guide them and sign post them to have a better life.

What do you enjoy most about your work?

- Being with my students.
- Dispelling myths and stereotypes about autism, plus showing job seekers that they are able to work and demonstrating to employers the benefits of a diverse workforce.

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- Working with children and young people to make a difference and seeing positive outcomes.
- Making a positive difference to people's lives.
- Being around children and their families. helping others.

What do you enjoy least about your work?

- Paperwork!
- Lack of funding, lack of understanding about how important support for adults with autism is (+25).
- Trying to get young people services when they transition to adulthood and don't meet the 'criteria' for adult services - particularly when they have various diagnoses including mental health problems. Also trying to get children accepted by the CAD team as their particular disabilities don't fit the CAD remit even though they have full EHCPs and full DLA.
- The number of hours worked each week!

Please tell us how you see your future as a care or teaching professional developing in the next few years.

- Hopefully expanding our clientele and increasing our numbers, to allow a wider range of options for our students.
- I am planning to train as a psychotherapist so that I can offer therapeutic input to adopted adults.
- I will continue to develop the staff who work for the company.

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Comment

Most spoke positively about their work. There is clearly some work to be done on Transition for those leaving childhood and moving into adulthood.

Theme: About the service in which you work

Please tell us how you feel about staffing where you work

- Proper contracts. More understanding from management.
- More funding in adoption.
- Increased funding.
- There are far fewer staff than needed.

Do you feel listened to and respected as a member of staff?

- Managers do not listen or respect us and have little understanding of SEND. We have constantly asked for the doors to be widened in our building, to allow better wheelchair access but there seem to be a lot of hoops to jump through to get this job looked at.

Do you think the service provider you work for is well managed?

- Need better understanding of SEND. Would also be useful to have more information about how adult funding works

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and where to signpost people to when they are not aware of things they are entitled to financially.

- My staff would affirm that the service us well managed.

Is the service responsive and well organised to meet service user's needs?

- Havering social services is too siloed so children and young people with a multiplicity of issues aren't consistently receiving the support needed e.g. via CAD team which definitely needs more funding.
- I believe the service users and their relatives would affirm that the service is responsive and well organised.

Is the service responsive and well organised to meet service user's needs?

- The staff in our department have an amazing relationship with the students and their families. They are dedicated and caring and encourage students to do things they may not usually be able or allowed to do. Students are safe and happy and enjoy coming to college - the routine is a huge factor in their quality of life.
- The passion and enthusiasm of the staff - This is necessary as unfortunately in our field of work the pay is not something that would keep somebody in a job.
- As my service isn't specifically for young people with autism or learning difficulties what is good is irrelevant to your particular survey but we do offer very high levels of support and therapeutic input

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- It is person centred.

What changes would you make to improve the service for the client group you work with?

- Widen the doors. Ensure all doors are suitable for wheelchair users. Magnetic fire doors, so doors can be left open to allow greater independence when moving around the building. Ensure more people at the council are aware that we are here and are an alternative to day centres.
- More support for adults, more funding for support into work.
- There should be more support for young people with complex diagnoses which comprise some form of learning disability as well as being adopted children - often the request is for adoption to give all the support when we aren't specialists in supporting children with disabilities.
- Open to suggestions from staff.

Have you any suggestions that would make where you work a better place to work for you and your colleagues?

- For Havering children's services to massively increase their offer via the CAD team - more social workers in that team and more support from adult services - joined up services across mental health and disability. Funding for adopted young people post 18 to have proper support.
- Funding.

Comment

The key issue mentioned in this feedback is understaffing – but, again, this is due to financing pressures outside the scope of this report.

4 Community Insights

Comments gathered by and recorded in the Community Insights System (CIS) [7] included several points relevant to this report, including (in no particular order):

- [There was] concern that ambulance crews sometimes had difficulty communicating with people with learning disabilities or autism, who might be non-verbal users of BSL or Makaton.
- They also told us that people with learning disabilities and/or autism [when visiting hospital] were not all comfortable about being given visible indicators of their special needs, such as coloured wrist bands, since that might draw unwanted attention to them. They preferred staff to be more vigilant and attentive without singling them out for special attention. They thought that some form of “digital passport” would be helpful.
- They told us that they had met a key member of staff from Queen’s Hospital who dealt with people with learning disabilities and autism and they had found having a person they knew on hand if they had to go to hospital reassuring and calming.
- My six year old child who has Autism was denied and refused a face-to-face appointment by a (GP) receptionist! Initially I had a telephone appointment three

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[7] CIS analyses feedback from a wide variety of sources across North East London to identify what local people think about the services they receive, and their experiences – good or bad – at health and social care facilities including hospital services, GP surgeries and care homes. These factors are then aggregated to produce Insights into how people view facilities overall.

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days ago where the Doctor stated that I need to book a face-to-face appointment for a full examination of my child's symptoms, but the receptionist decided not to provide a face-to-face appointment. The receptionists [at this practice] are on another level, stuck up shambles. Who are they to decide whether or not a child, who is clearly unwell, needs to be seen by a Doctor or not?!

- Disgusting experience at the A&E - I took my 5 year old (who had choked and stopped breathing) for a check up. Waited 5 hours and they kept saying we were next. After 5 hours of waiting the manager came out and made an announcement that they were extremely short staffed. We walked out as our child is autistic and we weren't able to make her wait any longer. I felt so sorry for all the poorly children and parents feeling helpless.
- New Doctor at [the practice] showed deep understanding with a lady with Learning difficulties severe, autism & challenging behaviour, added with health issues. **This was the first time a doctor at the practice has fully engaged in speaking directly about all women's health care without missing anything out in routine health check; the doctor encouraged the lady with so much care & understanding, all delivered in very small steps but allowing the time with no rushing at all** *[emphasis added]*. This was an Adult with Difficulties, allowed to speak for herself in her own words, at all times being supported within the appointment by carers.
- [Respondent has Asperger's disease and Autism spectrum disorder] I find mental health access somewhat harder. Covid stopped face to face assessments so my Asperger's diagnosis took much longer. Mental health cancellations

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have affected me a great deal. No useful alternative provided.

- My son was recently admitted to Queens Hospital in an emergency; as he has a learning disability, myself and my husband were allowed to stay with him. **Every single person working in A&E were some of the nicest people I have ever met. So a big thank you to all doctors, nurses and auxiliary staff**. *[emphasis added]*

Comment

The feedback reported above came from sources other than the three surveys on which the bulk of this report is based. Some comments came from other surveys we carried out on previous occasions.

It tends to support, however, the feedback from the surveys.

Conclusions

Most – though by no means all – feedback, from service users and carers is phrased negatively. Although they appreciate the support given to them by individuals, they are critical of the services through which support is, or should be, delivered. It is, of course, understandable that people who need support will always feel that not enough is available to them but, even allowing for that, they clearly feel that there is some way to go in delivering the services that people feel they need and, in some respects at least, are entitled to.

Many of the comments show that service users and carers feel that they are not listened to or are treated less favourably than more able people (which is potentially unlawful). It should not be – but plainly is – surprising when service users and carers comment positively about their experience with specific professionals (as shown in the comments gathered through Community Insights).

Clearly, there must be a balance between what the public purse can afford and what individuals need, want or expect, but whilst accepting that the financial climate at present is very restrictive and challenging, much could be achieved by reviewing not so much the cost of delivering services as the way in which they are delivered.

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We were surprised to learn that day care services for people with learning disabilities are not regulated, for example by Ofsted or the CQC. Whilst that is not an issue directly within the scope of this report or that local agencies can do anything about, we are going to raise the matter with Healthwatch England and local MPs with a view to suggesting that legislation be sought to provide for regulation in future.

An issue raised in the comments that affects not only service users living with learning disability or autism but many other people is the lack of changing facilities in public places for adults who have problems with incontinence. Again, this is an issue outside the scope of this report but it is one that requires broader consideration.

The feedback from those who responded to or surveys, and in the CIS data, provides a powerful commentary on the state of services for people who live with learning disabilities or autism, and of the support available to those who care for them, both informally and on a professional basis.

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Recommendations

We are acutely aware that the funding pressures on local authorities and the NHS are great, and thus that it would be very easy to string together a few “Mom and apple pie” recommendations that would be applicable in an ideal world with a bottomless “magic money tree” available to fund anything and everything.

But that ideal world does not exist and never will. Our recommendations have therefore been drawn up in the light of the feedback reported here from service users, their carers and the professionals working in the field who responded to our surveys.

Much of the anxiety reflected in the feedback could be reduced, if not eradicated, if only communication between service users, carers and health and social care professionals were improved. No one should be told to find another GP if they are unhappy with the practice where they are a patient; staff from all professional backgrounds should have greater awareness of the specific needs of people living with learning disability or autism and the problems attendant upon that; and carers should be kept better informed.

The following recommendations are accordingly made with these points in mind and based on the feedback we received in preparing this report. They are not presented in any particular order.

1 **That consideration be given to means by which people cared for by parents (or other relatives) can be prepared for the changes that will be inevitable when those who care for them are no longer able to do so.**

2 **That consideration be given to setting up some form of agency able to place people with learning disabilities and/or autism in suitable employment.**

3 **That, whilst accepting that this issue is outside the remit of this report, the extent to which it might be possible to relax the legal framework to facilitate access to service-users' money without compromising the essential safeguards be explored.**

4 **That the availability of clubs and safe and secure arrangements for getting to them for those that need such help be more widely advertised through Adult Social Care.**

5 **That the scope for reinstating "drop in café" facilities be explored.**

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6 That all staff working in health and social care environments who are likely to encounter service users living with learning disability or autism be required to undertake awareness training (and regular updating)

7 That all GPs and practices be reminded of their obligation to offer people with learning disability or autism an annual health check on a face-to-face basis with the intention of making a positive contribution to service users' health and wellbeing.

8 That GP practices – or PCNs on their behalf - arrange for the availability of wheelchairs or hoist scales for those service users who are unable to stand when undergoing their annual health checks.

9 That consideration be given by GPs to providing a dedicated phone contact line for use by people who are living with learning disability or autism and those who care for them in order to facilitate good communication.

10 That, recognising the difficulty they may experience in rapidly absorbing information, all service users living with learning disability and autism, and their carers, be given written information about their treatment after an appointment.

11 That consideration be given to setting up a register of dental practices that are "learning disability and autism friendly."

12 That consideration be given on a cross-agency basis for the appointment of a dedicated caseworker as a single point of access for service users and their carers.

13 That improved arrangements be made at Queen's Hospital to ensure that when patients living with learning disability and autism arrive, whether for planned care or A&E services, they are greeted appropriately and, where necessary, accorded the essential priority necessary to avoid causing avoidable distress or triggering challenging behaviour.

14 That all health and social care organisations' websites be reviewed and adjusted as necessary to ensure that information is available to service users living with learning disability or autism in terms and formats they can easily understand, with alternative means of communication available for their use.

15 That sensory training be made available to all schools, parents and professionals.

16 That awareness training be made available for school pupils on learning disabilities, autism, ADHD, and mental

health so the children understand these conditions and grow up supporting them and dealing with those affected with care and compassion.

17 That the avoidable barriers to people living with a learning disability or autism being able to enjoy freedom of movement or taking up suitable employment be addressed and, where possible, eradicated.

18 That opportunities for carers to become more closely involved in service development be identified and their participation encouraged accordingly.

19 That the Council and NHS North East London (who have the responsibility of commissioning all the health and community services) acknowledge that the description of Havering as "*one of the worst boroughs in London for their lack of care or empathy, assessment, assistance or anything to say the least*" is a wake-up call for the health and social care sector as a whole and take positive action to secure the improvements needed to meet the criticisms in this report.

Acknowledgements

We are grateful to everyone who participated in this project, whether in one-to-one discussions, in discussion groups or by completing the online surveys. The full and frank observations they made have provided powerful insights into the needs and aspirations of service users, those how care for them and the professionals who collaborate with them.

Whilst we have quoted numerous responses, it was necessary to edit some of them; that editing, and the interpretation placed upon the responses, are entirely the responsibility of Healthwatch Havering.

Participation in Healthwatch Havering

Local people who have time to spare are welcome to join us as volunteers. We need both people who work in health or social care services, and those who are simply interested in getting the best possible health and social care services for the people of Havering.

Our aim is to develop wide, comprehensive and inclusive involvement in Healthwatch Havering, to allow every individual and organisation of the Havering Community to have a role and a voice at a level they feel appropriate to their personal circumstances.

Members

This is the key working role. For some, this role will provide an opportunity to help improve an area of health and social care where they, their families or friends have experienced problems or difficulties. Very often a life experience has encouraged people to think about giving something back to the local community or simply personal circumstances now allow individuals to have time to develop themselves. This role will enable people to extend their networks, and can help prepare for college, university or a change in the working life. There is no need for any prior experience in health or social care for this role.

The role provides the face to face contact with the community, listening, helping, signposting, providing advice. It also is part of ensuring the most isolated people within our community have a voice.

Healthwatch Havering Friends' Network

Join our Friends' Network for regular updates and other information about health and social care in Havering and North East London. It cost nothing to join and there is no ongoing commitment.

To find out more, visit our website at https://www.healthwatchhavering.co.uk/advice-and-information/2022-06-06/our-friends-network-archive

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