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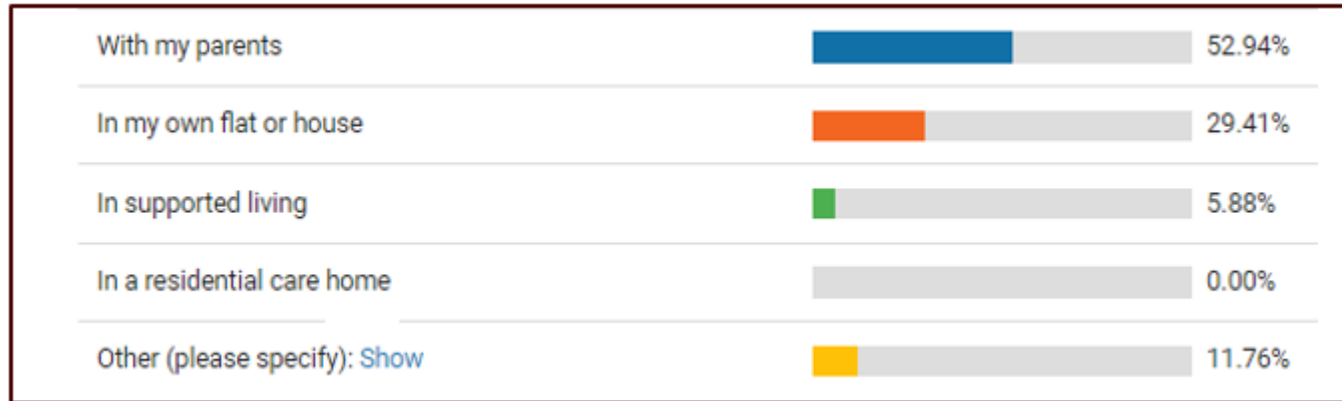
Community Engagement

Services for people living with learning disability and autism

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



Where do you live?



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



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



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.

Do you enjoy going to clubs?

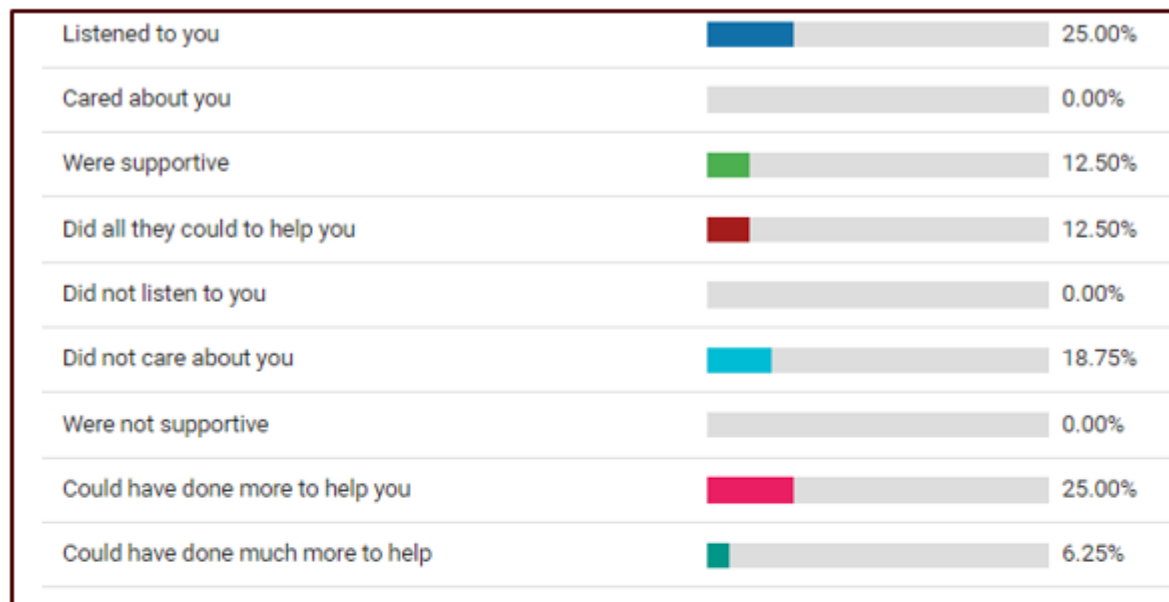


- There are none in Havering
- It is very hard to socialise with people due to them not wanting to mix with people that have a learning disability.
- Depends on your meaning for clubs. If it's nightclubs, no because of noise, drink etc. If its regular clubs, well, I'd like to find one I can attend comfortably.



LD & Autism: Service Users

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

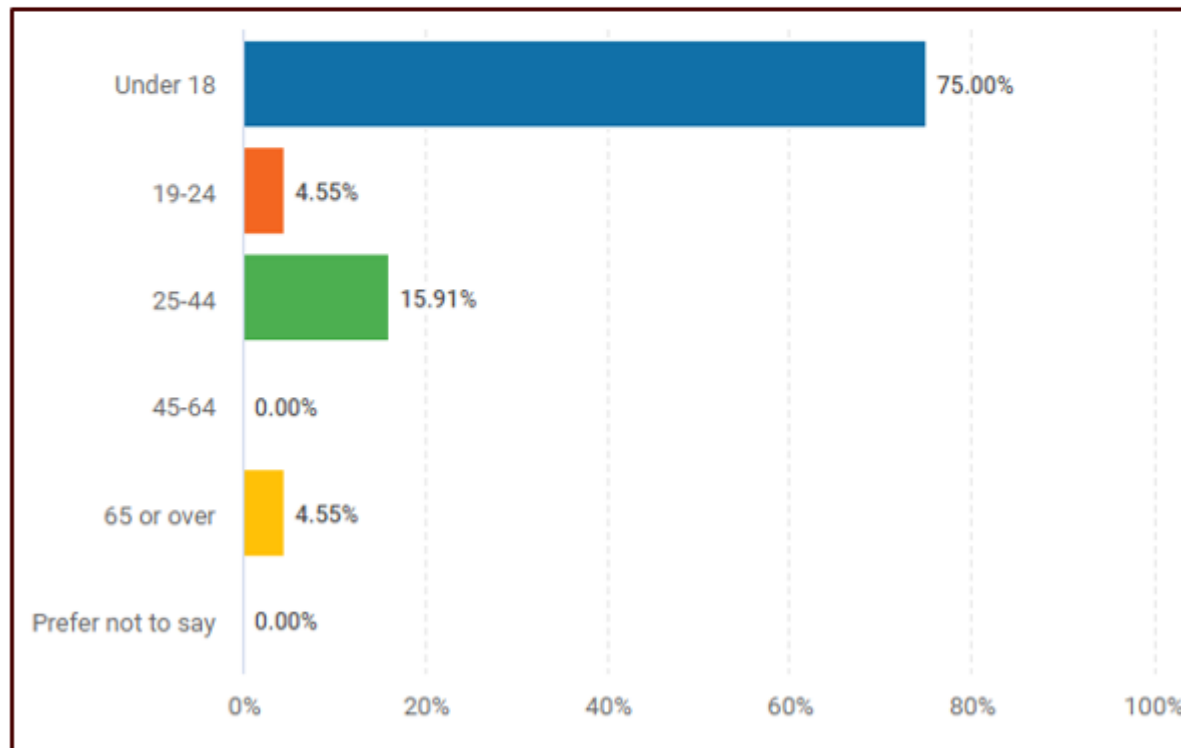


- [The] Receptionist has sniggered at me a few times which is very distressing and disrespectful. All staff should have LD awareness training, they have a duty of care to get medicine to me. **[I] told the GP [that I cannot have] BP tablets because [I have] falls in [my] flat. They still want me to take 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.



LD & Autism: Family, friends and informal carers

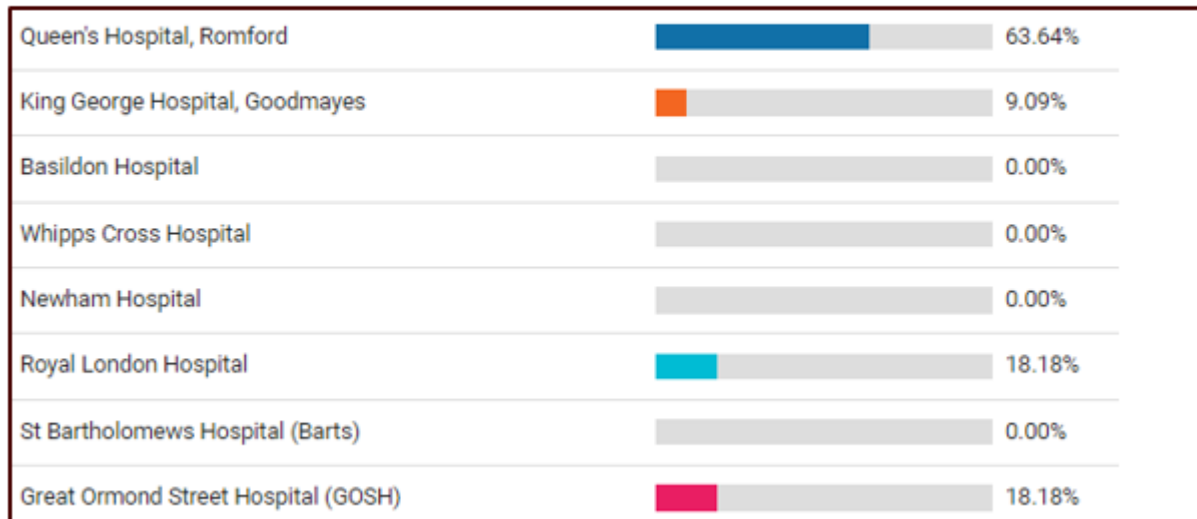
Although we aimed our survey at those caring for people living with autism or a learning disability of any age, three quarters of those who responded were caring for someone under 18 years of age:



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.
- 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.

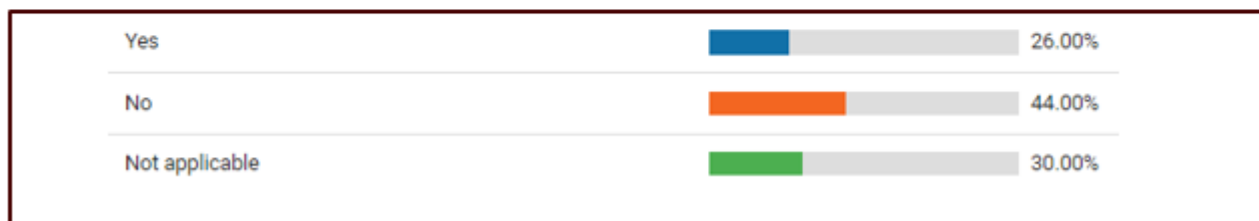


Again thinking about the hospital at which they were an in-patient for the longest time, how well do you think hospital staff were trained in meeting their needs?

- 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 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.



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



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?



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



LD & Autism: Family, friends and informal carers

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)



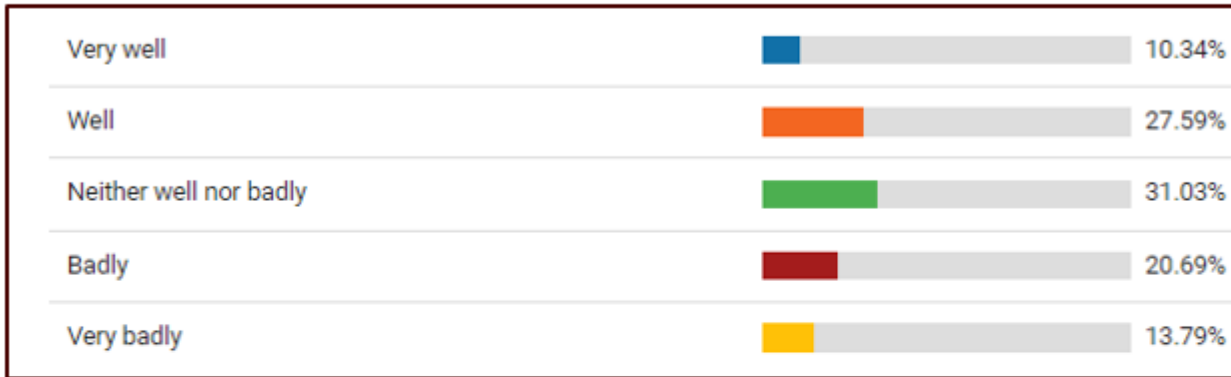
If you answered yes to the last question, did you accept the offer of a carer's assessment?



- This was done 3 years ago due to my own efforts and nothing else has been done thereafter.
- A complete waste of time!!



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.



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.

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.



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.

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.



- 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.**



- 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.**



Community Engagement

Deafness is not a barrier -

It only becomes a barrier if there is a lack of accessibility

Exploring how to improve access to care for the Deaf community in Havering



Key Messages

The National Deaf Childrens Society identifies 222 children with permanent hearing loss in Havering. The Community Connector team in Harold Hill led a discussion with parents of deaf children some of their concerns were

- *“More ambassadors for the Deaf community are necessary as there is a cultural, educational divide”. “Parents are worried that their children will be part of a ‘left behind culture”.*
- The Profoundly Deaf community is small in Havering: circa 1,000 people. However, the NHS estimates that by 2035, 1 in 5 people will have hearing loss.
- *Age is the single main factor and Havering has one of the highest number of older people in London - are we prepared?*
- For the Deaf community, GPs and Primary Care are the most consistent part of an individual’s care and wellbeing, they are also the key referrer to other parts of health and social care network
- *Our survey demonstrates that only a few GP practices are able to provide a responsive telephone service and most importantly very few have adequate and useful websites – how can we help to create greater accessibility and integration across health and social care?*



The difficulties of designing a service for the Deaf community when there is no formal or mandatory register

- ❖ It is estimated that by 2031, one in six people in London will have some form of hearing loss. Havering is most likely to easily hit this estimate due to its ageing population.
- ❖ For the Deaf community – unlike the Sight Loss community who have a registration process via a Certificate of Visual Impairment (CVI) – there is no mandatory register for the Deaf community. It is entirely voluntary and therefore the numbers of people living with Deafness are understated.
- ❖ It is a complex task trying to plan and design services for this community where there is land to estimate the level of support that is required
- ❖ There is concern that members of the Deaf community might be 'missing out' on a range of support and equipment.



What tools and advice are available to support the Deaf community and residents who have deafness to enable them to maximise benefits and support

- ❖ Many patients/residents are not aware that they may be eligible for additional support. A link with BHRUT would help the Borough to have a more accurate register. It will support access to benefits and concessions entitlements and eligibility to Disabled Freedom Pass.
- ❖ We reviewed the Havering Council website. We asked our members to try and navigate the website as a Deaf person, a carer, a parent of Deaf person and as a local resident. It was also compared with 12 Council websites across the country on access and information and the Havering website compared well.
- ❖ Increasingly Councils are introducing BSL videos and APPS on their websites and this would be an excellent addition to the Havering website as it improves communication with this community.



Thinking about how we approach and design ways of communicating and working towards creating an environment that encourages and supports the Deaf community -1

1. Consider strengthening the role and responsibility of the Havering Partnership Comms and Engagement Strategy group. Enabling them to review the wider determinants of effective communication and accessibility for the Deaf community
2. Give Deaf Young People their own voice. Could the Strategy Group, support the development of a Working group which was Chaired and led by young people who are Deaf, working with school/college, building young people's confidence, providing opportunities to practice presentations, acting as spokespeople on behalf of their communities and leadership.



Thinking about how we approach and design ways of communicating and working towards creating an environment that encourages and supports the Deaf community - 2

3. Start early with young children to create the opportunity of dual learning. Promoting co-learning enables the non-deaf child to become familiar with sign language and increases the opportunity of communication and understanding. CBeebies and Childline have good examples
4. The LBH website compared well with English websites. However, Scotland has made BSL a legal requirement from 2015 and their websites e.g. Dundee council, are very good and provide an excellent guide to what can be achieved.
5. To work with BHRUT to explore if there is the possibility that the Audiology department at BHRUT are able, with the consent of the patient, to supply the Audiogram results directly to the Council



GPs are experts in their patients and provide the first point of contact with the NHS for most people in Havering. People born with hearing loss need a lifetime of care and support, which should be co-ordinated and collaborative - and GPs are best placed to undertake this for patients - 1

- ❖ The Royal College of GPs has an excellent toolkit for GPs and we would encourage all GP practices to consider this approach
- ❖ For PCN's to consider identifying a person/ambassador to be the champion on behalf of GPs and Primary Care for Deaf people. This person would engage and be involved with the local Deaf communities on a regular basis. Linking the Deaf community to Local Area Coordinators and Social Prescribers



GPs are experts in their patients and provide the first point of contact with the NHS for most people in Havering. People born with hearing loss need a lifetime of care and support, which should be co-ordinated and collaborative - and GPs are best placed to undertake this for patients - 2

- ❖ Encourage the development of a Patient Participation Group (PPG) which has a focus on the Deaf, Autism and Learning disabilities communities. Encourage and nurture the PPG to lead the focus for annual health checks, developing relationships with interpreters etc.
- ❖ Ensure access for Deaf people to information and services at first points of contact
- ❖ Promote equal access in health settings, particularly in reception areas
- ❖ Provide clear and accessible information about treatment and management of health



GPs are experts in their patients and provide the first point of contact with the NHS for most people in Havering. People born with hearing loss need a lifetime of care and support, which should be co-ordinated and collaborative - and GPs are best placed to undertake this for patients - 3

GP websites now should be places where patients can complete tasks and practices can also deliver healthcare and services.

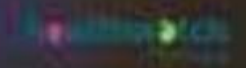
Develop a plan to assess the individual GP websites and rank them according to the Accessibility standards. Consider setting as baseline standards as the top 8 tasks that patients search for on a website:

1. Make, change or cancel an appointment
2. Get a repeat prescription
3. Get a sick note for work
4. Get test results
5. Register with/join the practice
6. Get the practice phone number
7. Find out the practice opening times
8. Find the practice address





BRITISH SIGN LANGUAGE CHOIR



To view the video, go to <https://www.youtube.com/watch?v=7BnnUsCUWzo&t=0s>



Community Engagement

Post-COVID Syndrome (Long COVID)

The continuing effects in Havering

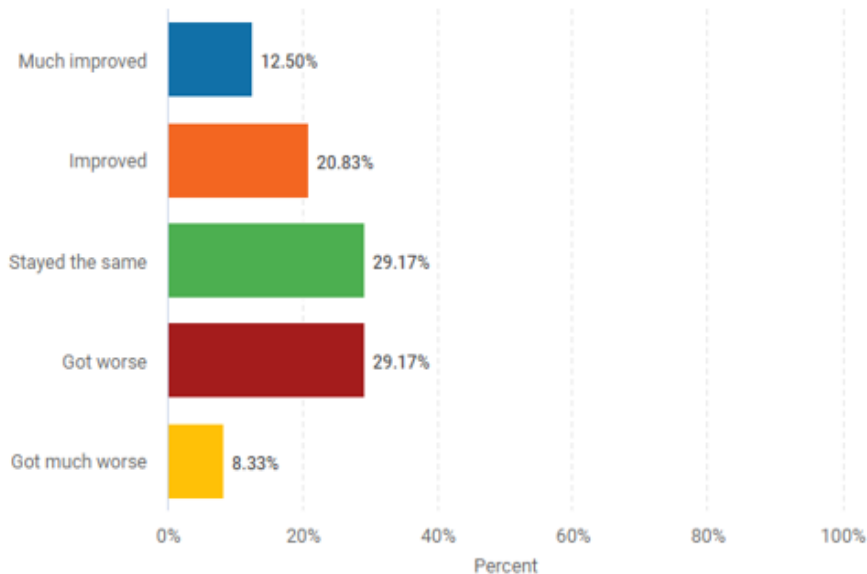


Post-COVID Syndrome (Long COVID)

The continuing effects in Havering



We asked the 23 respondents who had participated in our previous survey whether their condition had improved, stayed the same or got worse. They told us they had:



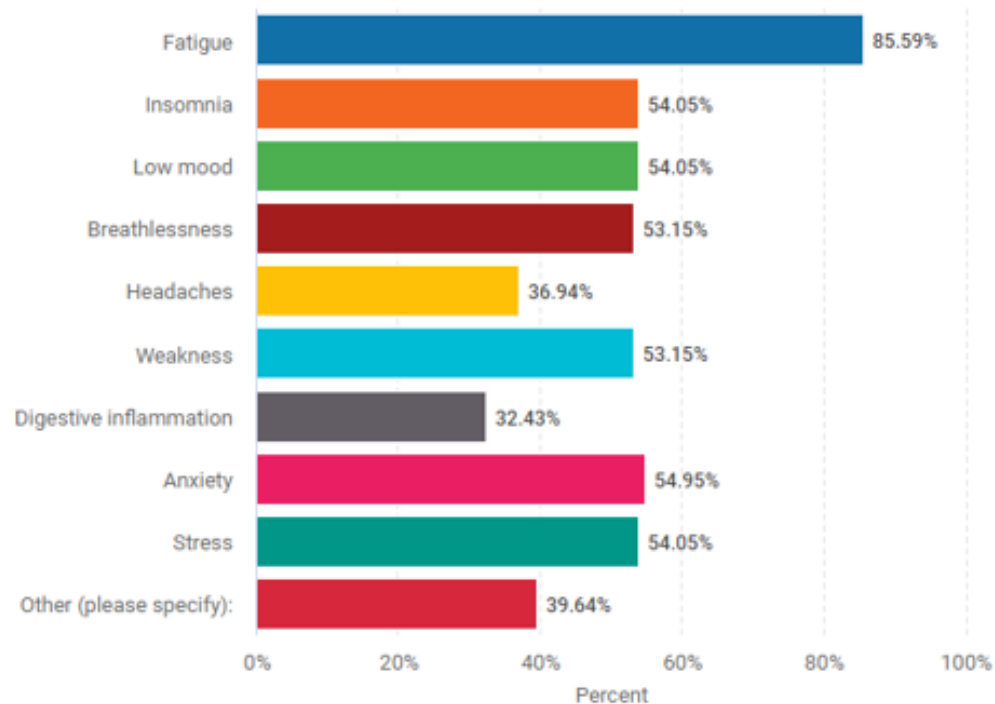
About a third (33.3% = 8) of respondents who had previously participated reported an improvement in their condition. Just over 29% told us there had been no change; and for 38%, the condition had worsened.



Post-COVID Syndrome (Long COVID)

The continuing effects in Havering

We then asked if these symptoms had continued for six weeks or more. They told us:



Post-COVID Syndrome (Long COVID)

The continuing effects in Havering



We asked what other symptoms respondents had experienced. They told us, among many others:

- Depression, insomnia, anxiety, stress, fatigue, dizziness, pins and needles, feeling sick and loss of memory
- Every week, I don't feel well. Either a cold or something else – always tired, cannot taste or smell properly, fatigue and aching joints
- Taste and smell took 18 months to return. Occasionally, I still lose my taste
- Muscle heaviness, brain fog, short term memory loss, poor balance, incontinence
- Poor smell. Poor taste. Difficulty in motivation to initiate tasks. Needing extra short sleeps.
- Brain fog, tremors, internal shakes, pains in lungs, nocturnal hypoxia



Post-COVID Syndrome (Long COVID)

The continuing effects in Havering



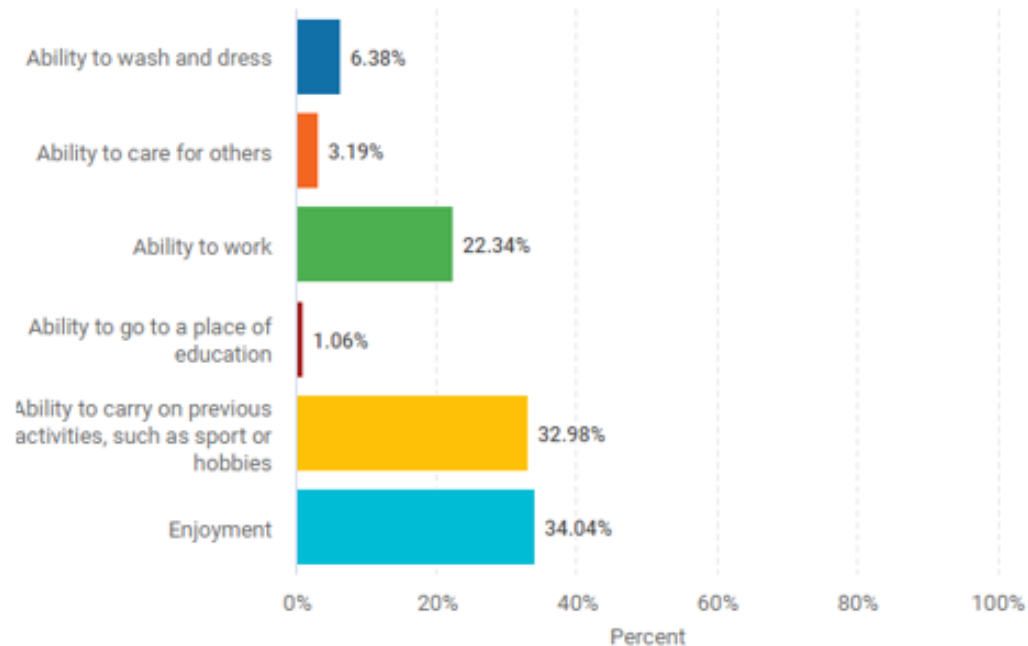
The term “brain fog” was mentioned many times in the responses. While not a recognised medical term, and varying from person to person, it clearly has a debilitating effect on those who feel that they are affected by it. It was associated with feelings of exhaustion, fatigue, tiredness and dizziness. Brain fog is mentioned throughout this report – it is clearly a significant symptom for many people living with Long COVID.



Post-COVID Syndrome (Long COVID)

The continuing effects in Havering

We asked whether they felt that their lifestyle had changed since developing Long Covid. Most respondents told us it had:



Post-COVID Syndrome (Long COVID)

The continuing effects in Havering



They told us, among many others:

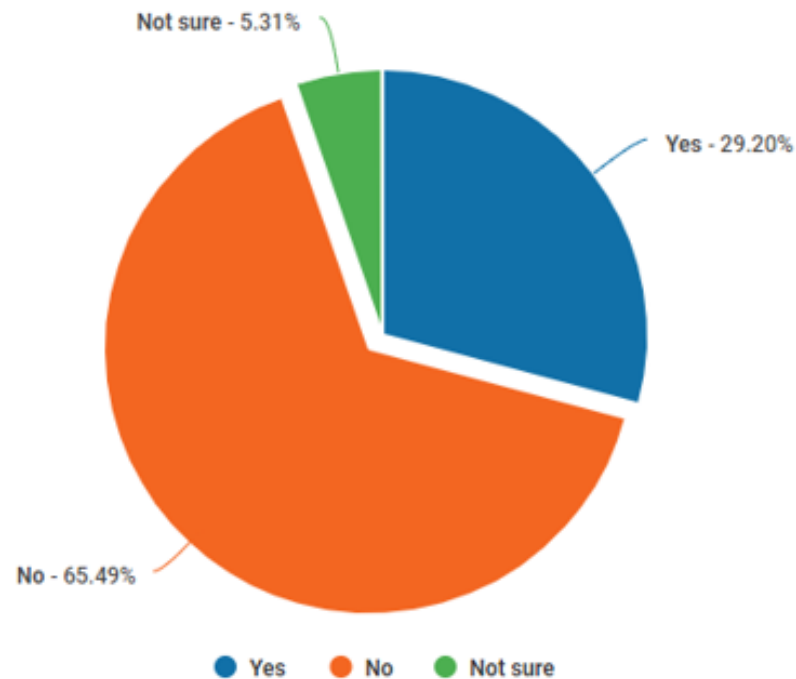
- I have lost interest in many things and find it hard to motivate myself due to the fatigue
- Secondary to my fatigue, breathlessness and frequent headaches, I have found it difficult to wash/dress on occasions, work has been far more challenging, despite now working from home, my previous activities and hobbies have been severely affected and this in turn has adversely affected my mood
- Not been at work/ can't do sports activities / enjoyment/can't take kids away or day trips to London A few hours out slower paced and exhausted



Post-COVID Syndrome (Long COVID)

The continuing effects in Havering

We asked if respondents had been referred for support for Long COVID. They told us:



Post-COVID Syndrome (Long COVID)

The continuing effects in Havering



We asked if there was anything else they would like to tell us about their experience or the support they had received. Some told us:

- My GP has supported me as far as he can (in my opinion). The system overall has failed me, I am still unwell, I have no confidence in the NHS providing information on an outcome. I am just left to get on with it
- All teams have been extremely helpful
- It was an eye opener to share the experience of others who have gone through the different stages of different episodes after COVID like myself
- Support was great. I do realise there are people worse off. But my life has changed completely since I had COVID e.g. loss of hearing in my right ear. I could hardly cope on a daily basis but had to work to make a living, change jobs in fear of getting COVID-19 again. My doctor referred me to the hospital, yet they didn't care. I have to keep moving forward.
- I feel like I have been left to deal with it on my own now after being discharged. My doctors haven't asked me how I'm doing. I've had to emails, texts or calls from the long covid team. Feels like they have said there's nothing we can do by now

Post-COVID Syndrome (Long COVID)

The continuing effects in Havering



Key word	Times mentioned	Key word	Times mentioned
Fatigue	32	Breathlessness	14
Tired	24	Anxiety	12
Brain fog	23	Memory	11
Breathing	23	Smell	11
Taste	17	No energy	7
Struggle	16	Exhaustion	5



Post-COVID Syndrome (Long COVID)

The continuing effects in Havering



The replies also suggest that there is some confusion among health care professionals about what is Long COVID and how to identify it: comments such as:

- “I’ve not had support”
- “Difficult to get a diagnosis”
- “I feel quite let down”
- “Have lost confidence in my GP”
- “My doctor said it’s too hard to diagnose”
- “My GP stated that long Covid support clinics mainly deal with breathlessness and not brain fog”
- It was the nurse in my GP practice who referred me to the health and well-being coach. My GP has offered no support or advice...” and
- “All I need is a proper diagnosis so my GP can move forward and support me more”



Post-COVID Syndrome (Long COVID)

The continuing effects in Havering



By contrast, we also received comments such as:

- “If my GP had not referred me to support, I would never have known about the help available”
- “My GP has been very supportive” and
- “One source of positivity has been Long COVID Kids charity”



Post-COVID Syndrome (Long COVID)

The continuing effects in Havering



In conclusion, it is evident that there is still an ongoing lack of awareness about Long COVID – how to diagnosis it and the support that residents can access. Continued training for healthcare professionals about the already established local clinical pathway would be beneficial.

Development of a clear non-clinical pathway may also ensure that residents can readily access support for symptoms such as fatigue, anxiety and brain fog. This may be through community groups or networks where they can share their experiences with others having similar experiences, rebuilding their confidence through mutual support and understanding. The worst feeling is to believe that one is alone in experiencing debilitation – knowing that others are “in the same boat” is often a source of comfort and strength for many people.

