An Insight Into Health and Care Access, Including Self-Care, for Adults with a Learning Disability

March - June 2023

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1.0 Introduction

1.1 Healthwatch Essex

Healthwatch Essex is an independent charity which gathers and represents views about health and social care services in Essex. Our aim is to influence decision makers so that services are fit for purpose, effective and accessible, ultimately improving service user experience. We also provide an information service to help people access, understand, and navigate the health and social care system. One of the functions of a local Healthwatch under the Health and Social Care Act 2012, is the provision of an advice and information service to the public about accessing health and social care services and choice in relation to aspects of those services. This document was revised in July 2022 and the role of Healthwatch was further strengthen as a voice of the public with a role in ensuring lived experience was heard at the highest level.

The Healthwatch Essex Information and Guidance team are dedicated to capturing the health and social care experiences people in Essex are meeting daily. The team respond to enquiries relating to health and social care and are equipped through training, to offer specific information to the public or other professionals. The team are well placed to listen, reflect on and support people to share complex experiences such as the one's shared in this report.

1.2 Background

Healthwatch Essex were approached by Hertfordshire and West Essex ICB to undertake a series of projects focussing on the lived experiences of people in the area in relation to their health, care and wellbeing. Two projects are selected per calendar quarter for in depth engagement, with the production of a report based on this engagement. For this project, we set out to gather lived experiences of neurodiverse individuals in accessing primary care services.

1.3 Acknowledgements

Healthwatch Essex would like to thank all the members of the public and professionals who took part in this project through the survey and interviews. Our thanks are also made to those individuals who took the time to meet with us and share their personal, heartfelt and emotive stories.

1.4 Terminology

ASD - autism spectrum disorder.
Developmental Jargon Aphasia - specific language impairment.
DLD - Developmental Language Disorder.
HFT- a national charity providing services for people with learning disabilities.
ICB – Integrated Care Board.
Irlen syndrome – a perceptual processing disorder.

LD - Learning Disability.
PAH - Princess Alexandra Hospital.
PEDs - Personalised Eating Disorder Support.
SLT - Speech and Language Therapy.
Wolfson Centre - research centre focusing on reducing anxiety and depression in young people.
DWP-Department of Work and Pensions.

1.5 Disclaimer

Please note that this report relates to findings and observations carried out on specific dates and times, representing the views of those who contributed anonymously during the projects time frame. This report summarises themes from the responses collected and puts forward recommendations based on the experiences shared with Healthwatch Essex during this time.

2.0 Purpose

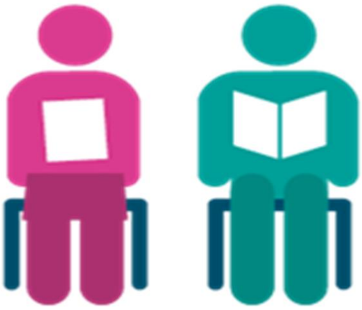
The aim of this project is to gather people's experiences of accessing and using primary care across west Essex. The focus was to gather feedback and lived experience from adults with Learning Disabilities and their carers/families and support workers.

2.1 Engagement methods

We connected with various organisations, including PACT for Autism, Families in Focus, Summit Services, Carers First, and ECL Day Centres to share details of our project and to share our Facebook page and website link requesting adults with LD, their carers, families and support workers for their feedback and lived experience regarding primary healthcare services. We also shared this request to numerous local Facebook groups in the west Essex footprint. The Facebook posts reached over 25,000 residents across this area.

Focus Groups

Group meetings were arranged in different settings to garner discussion and feedback.



Healthwatch Essex attended a local LD support group and talked to them about the project. There were sixteen adults ranging from aged 18-55 years old with LD and their support workers in attendance. The group were doing some arts and crafts when I arrived, they were colouring and drawing pictures for the upcoming coronation celebrations. The group also sat and ate a lunch together which had been prepared for them. One of the support workers introduced me and I explained who I was and why I wanted to talk to them. The feedback was varied:

‘It’s difficult to make a GP appoint at 8am. I suffer from anxiety, and I find this process very overwhelming and difficult to deal with.’

‘I make my own appointments, but I tell my mum, so she is aware.’

‘I attend my GP appointments with my mum as she is my carer but I get really upset when the doctor talks to her and not to me. It makes me feel like I don’t exist.’

‘I attend my annual health check and the doctor checks my blood pressure, sugar levels, heart rate, height and weight.’

‘The light at the dentist can be too bright, and this is uncomfortable for me.’

‘My mum orders my medication from the NHS app.’

‘My parents help me with all my medical appointments.’

‘I live in a house where I have a support worker from 8am-8pm every day. I make all my own doctors’ appointments.’

‘I am dyslexic and would find it easier to read forms/information/letters that are printed on yellow paper or have a yellow film available for me to use.’

‘I don’t go to my annual health check.’

This was the first time that I had met this group so some of them were shy and did not want to talk to me. Others were very comfortable and were happy to share their experiences. My main observation was how many of them relied on family members to assist them with their primary care needs. Many talked about how their parents are the people who make their appointments and manage any medication they need but that they also need to be recognised as individuals themselves and not just someone who is cared for.

Interviews

Individual interviews were conducted to collect personal stories. All participants gave their consent to have their interviews recorded. Participants were willing for their experiences to be shared within this report, however, to ensure their anonymity and confidentiality of information they provided, all names used are pseudonyms to protect identities.

Mary-Ann*

Mary-Ann has two adult children. She has a son who is twenty-two years and was diagnosed at thirteen years old with ASD and LD. He also has a rare Lymphatic condition which affects one of his legs.

She also has a daughter who is nineteen years old and was diagnosed with ASD at eighteen years old (there was a three year wait for an NHS assessment, so the family chose to have a private assessment). She also suffers from Diabetes and Anorexia. She is currently an in-patient at an eating disorder unit in East Anglia.

‘My daughter actually agreed to go to hospital because she had lost so much weight since December, but that was before her nineteenth birthday, so she was still eighteen. So, we had a really rocky road with her for the last year and a half, two years since she went into sixth form. Our journey with GPs, and in actual fact, not necessarily just with the GPs, but actually with the mental health service, has been absolutely appalling. First of all, two years ago the diabetic team said they wanted her to go to the eating disorder clinic. She agreed to go and see them down in Chelmsford for the PEDs. They said she didn’t have an eating disorder and said that it was all in her head and discharged her, which I actually think is totally appalling.

So that was one thing, not recognising her illness and then telling us it was all in her head and then we were bashing backwards and forwards. And of course, because of that being said, she felt that she had to prove a point. Children with ASD who are very high functioning will want to prove a point sometimes. So, she proved even more, and her anxiety got really, really high to the extent that she needed to be admitted. So, we were really let down by that service 100%. We then had to change GPs; we're on the border of West Essex and Redbridge. We live right on the border so our GP who is amazing is just on the border as well. The GP takes both West Essex and Redbridge patients. We've always had her care in West Essex; for her diabetes and everything, she was under PAH. She's now transferred over to Guys and Tommy's. That's only been a recent thing since Christmas around the same time as she was admitted. Saying that, they were really good but as soon as we said that we needed some support and her mental health was going down and they referred her into a crisis team because she was just crying and feeling overwhelmed with everything, we had someone come into the house from Redbridge, they came to the house and they said, this is what we can offer. The next day they came in and said, "I'm really sorry we can't offer you anything because you live in West Essex.'

Then of course our daughter, not knowing then that she was ASD even though we had known she had traits, of course she felt rejected. So, she'd been rejected twice, so that helped sent her mental health down more. Even coming into the house saying we can offer you this, then the next day coming back and saying, well really sorry, we can't offer you any services at all, so you just have to get on with it, is totally inappropriate. Out of all of this, it needs to be recognised that if you've got anyone who has a mental health problem, who is asking for help, it doesn't matter where you are based, you do not go into a house and say anything like that, especially to the person with a mental health problem. So, after that we had to then change GPs, as you can imagine that's been quite a difficult task. I'm quite lucky, I'm very knowledgeable of things. My background is such that I work with GPs sometimes. So, I work with multi agencies in the NHS, so I'm very lucky I can access things quite quickly and I know my pathways. 99% of people don't, and they've been struggling even more than I did. I did get a GP in West Essex after fighting and putting my foot down, but though then you only get support once a week. That is not going to be conducive to someone who's in crisis.

They focused on her anxiety and that was it, they didn't look at the eating part initially. We had a six-week programme of them coming in once a day initially because she was that unwell. They'd only come in for an hour, but she just closed down, she wouldn't talk to them. So, it was a bit of a losing battle to be honest. We then got discharged from them because they said there was nothing else they could do and of course, six weeks later she crashed and burned and was referred back to them. They decided then that it was an eating disorder. Oh, after a year, after we'd already said this is an eating disorder, they finally agree. So, then the eating disorder team came in lovely, they sent a lovely person, but they don't have the resources. In the meantime, we had got her diagnosed with her ASD, although it was privately done. She's in this unit now and we have been told that the piece of paper we have had done for the ASD assessment is not worth it because it's private. So now, a child who's still a very young person even though she's meant to be in adult services, has been told she can't have any of the services she needs locally because her ASD assessment that we were told by the NHS to get because there's a three year waiting list, we found the raised the money to get it done and they're not cheap, we've been told it's not worth the piece of paper it's on and that she ha' to have an NHS 'ne.

We will get through this, and I will find ways to help her so she can come out of where she is and get the right care she needs. But to go through what we've been through, it's broken the whole of our family, but it's not just once we've had it twice.'

Mary-Ann then talked about their experience with their son.

‘The first time was with our son when he was thirteen, he tried to take his life and then they took it seriously after me going backwards and forwards, backwards and forwards to the GP. He got a scholarship to the school he went to. He’s a bright kid, he dropped out of school at fourteen. He’s a really caring, loving person and he is really hardworking. He did decide he wanted to go into catering, and he got himself a place at college. He’s done the course; he got a distinction so he can do it. Although now his leg is causing problems, which is another setback because even though we haven’t declared it, it is a disability. When he bleeds, oh my God, he saturated the whole kitchen. It pulsates out when his leg starts to bleed so it’s hindering him from his work. So, they were quite good, and they did put things in place but of course if you’re catering, you do have to stand up the whole time. His experience with mental health services has been very poor. He can see when his anxiety’s high, but he doesn’t know how to deal with it because he’s got no one to support him to deal with it. And he’s been left to flounder. I do think it’s pretty disgusting.

I have to manage all his medical matters. Hopefully when he is 25, he’ll probably be a lot more able to do a lot of these things. But as we all know with ASD, that it’s a lot slower and especially if you’ve had some anxiety and problems, he still needs guiding a lot. A lot of reminding and I still need to do all the appointments for him; he’ll take the phone calls and then he’ll miss the crucial part, so I have to double check. He’ll sort out things like his medication but I’m normally the one who’ll make sure that the repeat prescription is done, I’m just about to change it over so that he can do it, but I think it will still be very hit and miss. It’s like my daughter, I still manage all her diabetic medication and everything. Get it delivered here and then I take to her.’

It’s just looking at ways differently; how can other people be helped so they don’t go through what our family have been through. They fall through the cracks; they fall through the network and then they have to be picked up. I know this sounds awful, but then it’s more of a financial burden on the NHS and for the services and for the general public. If we can get them early enough and sort this out and make sure there a clear pathway, it would be absolutely amazing. It does need to be a clear pathway but also there needs to be the resources initially, and I know people don’t always want to be the carers or the support workers because they say that it’s financially not worthwhile. But actually, that’s what we need, we need more mental health nurses and doctors, and we need definitely more on the eating disorder side, as they really lack resources.

I found out from a meeting that a third of Anorexia sufferers actually have ASD traits and are diagnosed eventually with ASD. So, if you are looking at that as even a starter, why isn’t there a specific pathway for that population? That’s still a massive population in that cohort. So, if people know this, why hasn’t this been looked at further and why isn’t there a certain care pathway to get them on the right path earlier? I know we had the added complication of a type one diabetic as well which was even more scary as you can imagine, but even then, people didn’t still jump until it was nearly too late. And that was with me jumping up and down every day.’

I asked Mary-Ann how well the different health teams worked together for her daughter due to her complex needs, including ASD, Diabetes etc.

‘So, that’s very interesting actually. The place where she’s gone is an eating disorder place, it is voluntary, but it’s got a really, really good name for itself. And actually, for the normal Anorexic pathway, it’s amazing. They are learning very quickly that my daughter is materialising to be a full-blown ASD person. Whereas initially they weren't listening to me saying, "This is what works best with your daughter." They're now coming back and saying, "Actually we should have done what you advised." But at least they are now looking for help for the ASD pathway.

I really think that the eating disorder team in Chelmsford for children needs to be called to account and re-evaluated as their service is absolutely appalling. Maybe it might not be had they got enough resources, but actually, I don't think my daughter would be nearly as bad if she hadn't plucked up the courage to go and see someone to get help and then to be told in a meeting that it's not an eating disorder, this is all in your head. It's not acceptable at all and it really needs to be highlighted that that service has failed. It failed a seventeen-year-old.

The other thing I'll say 's that you need continuity. So, they need to have at least three regular people, not a different person every single time. I know the resources are really minimal. I know people don't want to do the job and I can understand why they don't want to do the job. But if we're going to have it so it helps, that's what you need.'

I then asked Mary-Ann what support she has.

'Why would I get support? Come off it! I talk to my family; I've got my sister. I have my husband around, but he has mental health problems as well. So, I'm supporting him at the moment as well.'

Shirley*

'If anything happens to me, she has nothing.'

Shirley has a 31-year-old daughter, Amy, who has a Severe Developmental Language Disorder and numerous other health issues.

The local LD service has told Shirley that Amy does not meet their remit. Amy is also Autistic and has developmental jargon aphasia and dyslexia.

'Amy tries to live independently but currently has no carers; this service fell apart during the covid pandemic. She does have a LD social worker, but I have found that many professionals lack understanding or knowledge about her condition and how it affects her being able to do daily tasks. Amy has complex needs; she lacks insight, lacks stamina, she doesn't really understand what's going on in the world. What you see isn't what you get with her, she is a crowd pleaser and will say yes to everything even though she doesn't understand what she is saying yes to.

I must make and attend all her GP appointments, I then have to debrief her afterwards, so she understands what happened during the appointment. All her medication is in Dossett boxes. I try to remind her what she needs to do but she sees it as nagging. Reminders are sent to her for eye tests, but these can get missed if I am not aware of them. Amy does not have an annual health check.

She also has lots of anxiety issues; she was seeing the mental health team where she used to live but not where she currently lives. She was told to phone the Samaritans if she needed help, but this is not an option due to her language disorder. I have not been able to access any speech or language services for her, the GP has also tried but with no success.

This is some information from her Neuropsychological report. Her ability to hold onto heard information is low, her vocabulary is extremely limited, and she has difficulty generating the abstract relationship between words. The most striking aspect of Amy's performance was her difficulty with language tasks. Her ability to name objects is very poor though she does much better with familiar than unfamiliar objects. She has difficulty with the production of complex phonology which affects the level of complexity of her utterances. Her speech tends to be more comprehensible the shorter it is. This profile is characteristic of a specific language impairment (SLI), a developmental disability that selectively affects language especially. This is not usually classified as a learning disability because of the fact that performance on non-language tasks is often within normal limits. However, it is a learning disability in fact because overall education and the ability to function normally in many aspects of function in daily life are adversely affected by the poor language competence of these patients.

Unfortunately, I have had to deal with a couple of outbursts from Amy about situations that have caused her distress (anxiety and anger causes her language skills to drop) and it has taken all my energy to pull her out of a spiral of decline in order for her to function. Plus, chasing and asking HFT to contact the social worker for questions to give Amy time to think about what will be asked and formulate her answers for her up and coming meeting with social care, has taken up a lot of time. Of course, this has had a huge impact on my current health, which isn't good at the moment, and I have to schedule time to rest to recuperate.

I have two reports from the SLT and the neurologist regarding Amy's condition. When I asked the GP about a referral, they completed one for SLT; he stated it was sitting on a manager's desk but so far, we have not heard from anyone. This referral was primarily to ensure the social worker understood what and how Amy's language impacted function, as all the social workers so far, do not understand developmental language disorder nor female autism. HFT chased this up but was told that all SLT's are being used for swallowing difficulties.

Just to help you a little about the extent of Amy's language problems; she has damage with receptive, expressive speech, auditory processing disorder, word finding difficulties and working memory problems as well. We were also told by Professor Vargha-Khadem that she has lesions all over the brain and it has had an impact on neurological plasticity. Lucy's language disorder is unique, which is why we were catapulted to the Wolfson Centre when we eventually found a paediatrician who was interested and mainly had professors involved with her healthcare. Local services were not really involved, as it was beyond their knowledge, but DLD is not unusual, it is just ignored.

I have her last school report and her initial social care report when she left school that are particularly insightful and a vast range of other reports detailing anxiety disorder, dyslexia, Irlen syndrome, dyspraxia, Autism (late diagnosis) and development jargon aphasia to name but a few, if needed. Sadly, we are still uncovering healthcare problems and arguing for her to be diagnosed, with the latest being a problem with the HPA axis.

I hope this helps you to understand a little about my daughter, she is certainly not for the faint hearted, which is why we struggle with services.'

Darren*

Darren has three adult children who have a combination of LD, ASD and other medical conditions.

‘My son needs 24-hour care and support; he hasn’t been in any sort of education or training for over three years now. A place was found for him to attend college, but I would have had to pay for a private taxi to get him there and back which was unaffordable. I am unable to work myself at the moment due to my own health issues. He is unable to attend benefit interviews on his own, he doesn’t understand what is happening and I have to speak for him. This makes the process really difficult and stressful for both of us. He will never be able to hold down a ‘normal’ job so why do we have to attend face to face interviews with DWP. The staff do not know how to communicate with him, so it’s all left up to me.

He can’t cope with going to the dentist, having any sort of equipment coming towards him really freaks him out. Going to the GP is also difficult, the environment is too busy and noisy, it overwhelms him, and he becomes difficult to manage. Why can’t GP’s have ‘quiet’ times like cinemas and supermarkets? He has never been offered an annual health check.

My other two children are able to work but still need a certain amount of support. They have had no input from any sort of adult services regarding their LD.’

Chris*

Chris has LD and is Autistic.

‘I can’t access care from my GP because you can only use the phone and I have anxiety, non-speaking episodes and audio processing difficulties. When I have attended the practice there are no accommodations for my sensory difficulties on offer and I am close to meltdown by being kept waiting in a busy, bright, noisy waiting room for long periods of time. A GP at my practice glanced at my diagnoses and said, “oh to look at you, you wouldn’t think you had all these problems, you just look normal.” I could go on but basically GP services are inaccessible.’

3.0 Key Findings and Recommendations

The main observation from our period of engagement was how many adults with LD rely on family members/carers to manage their health appointments and medication. Many need that level of support to monitor, make and attend appointments when required. This puts pressure on family members/carers to remember when health checks etc are due and to make sure that their loved one is prepared, understands why these checks need to be done and what the process is. This alone can take a great deal of time to explain and prepare for. GP's surgeries can be noisy and too busy for some adults with LD to cope with. This can be a barrier for them attending annual health checks. The process of phoning a GP surgery at 8am to try and make an appointment can also be a barrier for accessing primary care. Many people stated that this process was overwhelming and caused anxiety. Some people had carers who came in at certain times during the morning so were not always able to be there to make a phone call at 8am. Again, this could take days before an appointment was finally made. Talking to the person who the face-to-face appointment is for is vital for them not to feel excluded, one participant said that when the GP talks to his mum and not him during his appointment it made him feel like he didn't exist.

Routine dental and optician appointments were sometimes missed due to inappropriate communication. Some services dealt with the adult with LD directly and this led to appointments being missed and checks becoming overdue.

Some adults are able and confident enough to manage their own medical appointments with little or no support from family/support workers.

Adults with LD and other health conditions, such as ASD, speech and language conditions etc have struggled to access appropriate services, and often the combined issues have not been dealt with in an holistic manner and this had led to family/carers not being able to access what is required for their loved one. This has meant that other family members, usually parents are left to deal with the situation on their own with limited support/advice. The fight to find the right services puts immense pressure on an already stressful situation. Mental health services were highlighted as being inadequate to meet the needs of people with LD, it was difficult to access these services and then people were often discharged without any treatment and being told that there was nothing they could do for them. As one individual told us, 'Trying to get mental health support for someone with a learning disability is quite disgraceful, I am a carer and cannot get the help needed.'

Recommendations:

- An inclusive communications drive to promote annual health checks, dental and eye check-ups. Using social media, easy read documents, short videos and letters to adults with LD and their families/carers. Links to some useful examples: https://www.england.nhs.uk/learning-disabilities/improving-health/annual-health-checks/

  AHC Easy Read Guide Final.pdf (mencap.org.uk)

- Ensuring that correct contact information is on the GP learning disability register; is the adult with LD able to be communicated with directly or does it need to go via a family member or caregiver? Is it the correct form of communication that they can access and understand, phone calls, letters, text messages, is it up to date etc.

- Explore the possibility of LD friendly/appropriate GP session times with reduced noise levels, less people in the waiting room etc. Does the person need a double appointment to make sure there is time available in case they struggle with the situation and need extra time to adjust so the appointment is productive?

- Having one point of contact for the adult and their support network will help to build a relationship and confidence with a medical professional. This will also reduce the number of times that the persons situation/needs have be repeated.

- Focused training for frontline staff-receptionists as well as medical staff to raise awareness and understanding of people with LD and their needs. Taking the time to listen and understand that what could look/feel like poor behaviour could be frustration at not being understood.

- Examples of good practise as highlighted in the Healthwatch Essex Part of Understanding Inequalities: Co-Designing accessibility to health services in Mid and South Essex.

Our engagement and initial scoping activities highlighted existing projects, in other localities, that have improved support for patients with learning disabilities. Examples of these initiatives include:

Queensway Surgery, Southend: A practitioner there has led the way in promoting best practice when caring for patients with learning disabilities. She has a strong understanding of how to communicate with patients, improving the uptake of annual health checks and earning the practice more income as a result.

Thurrock Health Centre has developed a 'Learning Disability Mission Statement' that showcases their 'philosophy of care' for patients living with learning disabilities. The statement, which can be found here, expresses the Health Centre's commitment to enhancing staff awareness about learning disabilities. Staff aim to work as a team with patients, families and carers to provide patients 'the best individualised care, whilst maintaining their dignity, privacy and freedom of choice'. The Learning Disability Co-ordinator at Thurrock Health Centre is Michelle Webb.

Purple All Star Strategy was established by Hertfordshire County Council and the University of Hertfordshire's Business School in 2014. The Purple All Star is a trademark given to GP Practices in Hertfordshire that demonstrate a commitment to bridging the health inequalities gap faced by people with learning disabilities and taking steps to ensure equitable health outcomes. GPs are supported by the scheme to achieve and maintain the standard. There are currently thirty accredited surgeries in Hertfordshire that have fulfilled 15 criteria areas, including having a learning disability champion, using the learning disability register, and displaying evidence of good practice, including strong annual health check performance.

Martin Hill, Louise McKay, Charles Theisinger, Yasmin Ellis, Alex Fletcher, and Joanne Tyler, 'Improving the quality of Learning Disability Annual Health Checks' (Mid and South Essex Health and Care Partnership, 2020): This quality improvement project aimed to understand the quality of Annual Health Checks being conducted in West Central PCN in Southend; responding to a lack of available data on the quality of checks being completed in mid and south Essex. The project provided recommendations for how Annual Health Checks should be promoted to the public. The authors called for GP surgeries to adopt communication that was specific and sensitive to individual patients. Seeking to promote and complete the health checks en masse served to depersonalise the process and alienate prospective patients.

The project aimed to increase the number of Annual Health Checks completed in the West Central PCN. They also recorded how the checks were conducted with individual patients; measuring whether GPs were completing all key elements of the check. One of the authors later noted that GPs completing checks would sometimes overlook questions about sexual health, therefore reinforcing the stigmatising assumption that people with learning disabilities do not engage in sexual activities. The authors also designed an audit tool that identified good practice, enabled monitoring of progress, and established whether support for patients with learning disabilities was consistent across a geographical area. There was little information, however, on how to successfully engage with and support patients with learning disabilities during the health check itself.'

4.0 Conclusion

Even though the engagement for this project was somewhat lower than anticipated, it is important to value and recognise the lived experience and feedback that was gathered.

Due to the complex needs of many of the people I spoke to, remembering to attend routine health checks was one of many ‘jobs’ that needed doing and were often put on the back burner while day-to-day life needed to be dealt with.

The people who did attend their annual health check generally said it was a positive experience and understood why they went.

Ensuring that adults with LD are treated with respect and understanding is the key to building a positive relationship so they are more willing to attend routine health checks and have a positive experience. All staff involved in the process of encouraging adults with LD to attend regular health checks need some knowledge and understanding of that individual's situation and support network makeup so effective communication is implemented.

This project highlighted how complex the needs of some adults with LD can be, this means a number of health professional can be involved in their care which can lead to confusion and uncertainty regarding who is leading which aspects of their care. There can be a high turnover of consultants/social workers/care staff etc which can also lead to confusion when people are trying to contact the people who are meant to be supporting them. Multi agency and team working is vitally important in this situation to ensure continuity of care is delivered and that person receives all the services that they require to live a full and healthy life.

Access to appropriate mental health services was also highlighted as many family members stated that their loved one was often discharged by mental health teams as they didn’t meet their remit. This leaves already venerable people in limbo with no access to support. Carers support is also a vital part of making sure the network around the adult with LD is as stable as it can be. Identifying carers and asking them what help/support they may need is extremely important.

Taking ideas and learning from good practise in neighbouring ICB’s/ICS’s will help towards developing a plan which is effective and delivers consistent long-term results.