



Exploring how Adults with Learning Disabilities are supported by GP Services in Hertfordshire

Engagement: February – May 2023

Published: November 2023

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healthwatch
Hertfordshire

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About Healthwatch Hertfordshire

Healthwatch Hertfordshire (HwH) represents the views of people in Hertfordshire for health and social care services. We provide an independent consumer voice for evidencing patient and public experiences and gathering local intelligence with the purpose of influencing service improvement across the county. We work with those who commission, deliver and regulate health and social care services to ensure the people's voice is heard and to address gaps in service quality and/or provision.

About the Hertfordshire and West Essex Integrated Care System (ICS)

The Hertfordshire and West Essex Integrated Care System (ICS) was established as a statutory body on 1st July 2022. Integrated Care Systems are geographically based partnerships that bring together providers and commissioners of NHS services with local authorities and other local partners to plan, coordinate and commission health and care services¹. The Hertfordshire and West Essex ICS is made up of two key bodies – an Integrated Care Board (ICB) and Integrated Care Partnership (ICP).

Integrated Care Board (ICB)

The Integrated Care Board (ICB) is an NHS organisation responsible for planning and overseeing how NHS money is spent across Hertfordshire and West Essex, with the aim of joining up health and care services, improving health and wellbeing, and reducing health inequalities. The board of the ICB includes representation from NHS trusts, primary care and from Hertfordshire County Council and Essex County Council².

This report will be sent to the Hertfordshire and West Essex ICB Primary Care Board to inform how it can improve the support people with learning disabilities receive from their GP practice.

Integrated Care Partnership (ICP)

The Integrated Care Partnership (ICP) is made up of representatives from different organisations involved in health and care. This includes NHS organisations, local authorities and the Voluntary, Community, Faith and Social Enterprise (VCFSE) sector. The partnership is responsible for developing an Integrated Care Strategy which will set out the priorities for Hertfordshire and West Essex for the next 10-20 years³.

Hearing Patient Views about Primary Care in Hertfordshire and West Essex

Hertfordshire and West Essex have been commissioned by the Hertfordshire and West Essex Integrated Care Board (ICB) Primary Care Workstream to undertake a series of engagement projects. The aims of the engagement projects include:

¹ [Integrated care systems: how will they work under the Health and Care Act? | The King's Fund \(kingsfund.org.uk\)](https://www.kingsfund.org.uk/insights-and-analysis/healthcare-reform/integrated-care-systems)

² [Health and wellbeing decisions – Hertfordshire and West Essex Integrated Care System \(hertsandwestessexics.org.uk\)](https://www.hertsandwestessexics.org.uk/health-and-wellbeing-decisions)

³ [Health and wellbeing decisions – Hertfordshire and West Essex Integrated Care System \(hertsandwestessexics.org.uk\)](https://www.hertsandwestessexics.org.uk/health-and-wellbeing-decisions)

- Gathering lived experiences to feed directly into the Hertfordshire and West Essex ICB Primary Care Workstream
- Supporting and enabling the Hertfordshire and West Essex ICS to achieve wider participant engagement
- Engaging patients and the public on programmes covering key priorities and areas of importance at a regional and local level
- Making recommendations to the Hertfordshire and West Essex ICB Primary Care Workstream so improvements can be implemented

Using patient and public feedback, each engagement project will focus on improving the relevant service(s) within different areas of primary care by making recommendations to the Hertfordshire and West Essex ICB Primary Care Board.

From February to May 2023 the Director of Primary Care Transformation at the ICB requested Healthwatch Hertfordshire and Healthwatch Essex to explore the experiences of adults with learning disabilities in accessing GP services, and how they are supported by GP services to live a healthy lifestyle.

Background

There are approximately 1.5 million people in the UK who have a learning disability⁴ and an estimated 21,000 people with a learning disability living in Hertfordshire⁵. People with learning disabilities tend to experience much poorer physical health outcomes and are more susceptible to a range of health conditions compared to the general population⁶. For example, rates of cardiovascular disease, respiratory disease, cancer, obesity and Type 2 Diabetes are significantly higher amongst people with a learning disability than the wider population⁷.

As a result, people with learning disabilities are far more likely to have a lower life expectancy. In 2022, the Learning Disability Review of Mortality (LeDeR) found that the median age of death for people with learning disabilities in Hertfordshire was 58 years old⁸. This is considerably lower than the median age for the general population at 81 years old⁹.

However, it is very important to recognise that these differences in health are largely avoidable, meaning that deaths and ill health could be prevented through the provision of good quality healthcare¹⁰. In Hertfordshire, 59% of the causes of death of people with a learning disability would be defined as avoidable causes of death, compared to 22% for the general population¹¹.

These figures show how crucial it is that the health needs of people with learning disabilities are addressed by clinicians early, and that they are given the appropriate care, treatment and support. A significant factor for this inequality is difficulty using healthcare services and barriers to accessing healthcare.

Barriers to Accessing Healthcare

Accessing Appointments

⁴ [How Common Is Learning Disability In The UK? How Many People Have A Learning Disability? | Mencap](#)

⁵ [SEND news - \(hertfordshire.gov.uk\)](#)

⁶ [NICE impact people with a learning disability](#)

⁷ [NICE impact people with a learning disability](#)

⁸ [LeDaR Annual Report 2021-22 \(hertfordshire.gov.uk\)](#)

⁹ [Life expectancy for local areas of the UK - Office for National Statistics \(ons.gov.uk\)](#)

¹⁰ [learning-disabilities-jsna.pdf \(hertshealthevidence.org\)](#)

¹¹ [LeDaR Annual Report 2021-22 \(hertfordshire.gov.uk\)](#)

People with learning disabilities can face significant challenges in accessing health and care services. Many can find it difficult to make an appointment with health and care services, as online services are often difficult for people with learning disabilities to use and access, and visiting in-person can also be inaccessible due to factors such as money, location and transport. Long waiting times on the phone and speaking to a receptionist can provoke unnecessary stress and anxiety¹². All of which can make people with learning disabilities feel hesitant to contact healthcare services, despite needing medical attention.

People with learning disabilities also tend to rely on their carer or support worker to help them make an appointment and to be in attendance. Flexibility around appointment times and dates is very important to ensure that someone with a learning disability can be supported by their carer or support worker. When this is not accommodated for, this can mean having to wait several weeks for an appointment¹³.

Choice in the type of appointment is imperative, with most people with learning disabilities preferring to discuss their concerns in-person. Face-to-face appointments are also important, as people with learning disabilities can have difficulties communicating their health needs and whether they are in pain¹⁴, which can lead to challenges identifying health conditions and delays in diagnosis and treatment. By seeing a clinician in-person, the patient can have a physical examination to ensure any concerns are addressed.

Similarly, being able to see their usual clinician is essential to people with learning disabilities, as this familiarity and continuity of care can help them to feel more comfortable and as such, help them to communicate their needs and symptoms with greater ease¹⁵.

Communication Barriers

People with learning disabilities can find it more often to communicate, and health information in particular can be hard for them to understand and engage with¹⁶. Research has shown that not meeting their communication needs can lead to incorrect diagnoses, inadequate care and inappropriate medication given¹⁷. Despite this, clinicians often lack training, understanding and awareness as to how to communicate with people with learning disabilities in a way that is accessible to them.

Fear and Physical Environment

People with learning disabilities can feel scared speaking with clinicians. Fears include judgement over their lifestyle choices, blood tests and vaccinations, use of medical instruments and concerns around screening procedures¹⁸. It is also common for people with learning disabilities to find clinical environments or waiting rooms uncomfortable and distressing¹⁹. All of which can make people with learning disabilities reluctant to access healthcare services, and emphasising the importance of ensuring settings are made accessible and safe for people with learning disabilities.

Barriers in Living a Healthy Lifestyle

¹² Meeting in the middle: improving communication in primary health care consultations with people with an intellectual disability: *Journal of Intellectual & Developmental Disability*: Vol 29, No 3 (tandfonline.com)

¹³ (PDF) What should dental services for people with disabilities in Ireland be like? Agreed priorities from a focus group of people with learning disabilities (researchgate.net)

¹⁴ Pain and pain assessment in people with intellectual disability: Issues and challenges in practice – Doody – 2017 – *British Journal of Learning Disabilities* – Wiley Online Library

¹⁵ Barriers and facilitators to primary health care for people with intellectual disabilities and/or autism: an integrative review – PMC (nih.gov)

¹⁶ (PDF) What should dental services for people with disabilities in Ireland be like? Agreed priorities from a focus group of people with learning disabilities (researchgate.net)

¹⁷ Why some adults with intellectual disability consult their general practitioner more than others – Turk – 2010 – *Journal of Intellectual Disability Research* – Wiley Online Library

¹⁸ Barriers to healthcare: Instrument development and comparison between autistic adults and adults with and without other disabilities (sagepub.com)

Addressing barriers in accessing healthcare is important, however it is also imperative that GP services play an active role in supporting people with learning disabilities to live a healthy lifestyle, particularly given that they are far more likely to face poorer physical and mental health outcomes, as outlined below.

Obesity and Inactivity

People with learning disabilities are at an increased risk of being overweight or obese compared to the general population²⁰, with data identifying that 37% of people with learning disabilities are obese compared to 30% of people without a learning disability²¹. This is often due to poorly balanced diets and lower levels of physical activity. This risk increases the likelihood of a range of health problems, including heart disease, high blood pressure, stroke, Type 2 Diabetes, types of cancers and mobility difficulties²².

People with learning disabilities tend to have poorer health literacy²³, and can find it more difficult to understand information about healthy eating, exercise and weight management, and the benefits of being active and making healthy choices²⁴. They can also find it more difficult to cook and prefer healthy meals, often resorting to eating ready-meals which can be high in fats and sugars²⁵. Lastly, exercise facilities such as gyms and swimming pools can be inaccessible, including difficult to travel to, expensive and unwelcoming²⁶.

Mental Health

People with learning disabilities are at greater risk of experiencing poor mental health, with severe mental illness 8.4 times more common in people with a learning disability than those without²⁷.

Research has also found that 36% of people with a learning disability felt lonely nearly always or all the time. 37% said they hardly ever or never go out to socialise, and 33% said they did not feel part of their local community²⁸.

Health and Wellbeing

Research shows that some groups of people with learning disabilities are less likely to partake, but are at an increased risk of smoking, drinking alcohol in excess and using illicit and/or prescribed drugs²⁹. Such behaviours can lead to physical and mental health complications.

Although people with learning disabilities are less likely to be in a relationship and pursue sexual relationships, this remains an important matter as they are less likely to understand information about sexual health, including contraception, sexually transmitted infections and pregnancy³⁰.

Cancer Screenings

²⁰ [Obesity and weight management for people with learning disabilities: guidance - GOV.UK \(www.gov.uk\)](https://www.gov.uk/guidance/obesity-and-weight-management-for-people-with-learning-disabilities)

²¹ [Improving the diets of people with a learning disability \(learningdisabilitytoday.co.uk\)](https://learningdisabilitytoday.co.uk/improving-the-diets-of-people-with-a-learning-disability/)

²² [The Medical Risks of Obesity - PMC \(nih.gov\)](https://pubmed.ncbi.nlm.nih.gov/26111111/)

²³ [Improving the diets of people with a learning disability \(learningdisabilitytoday.co.uk\)](https://learningdisabilitytoday.co.uk/improving-the-diets-of-people-with-a-learning-disability/)

²⁴ [Don't Mention the Diet! A health promotion initiative to support healthy diet and lifestyle decision-making by people with intellectual disability - Martin - 2021 - British Journal of Learning Disabilities - Wiley Online Library](https://www.bjld.org.uk/journal-articles/dont-mention-the-diet-a-health-promotion-initiative-to-support-healthy-diet-and-lifestyle-decision-making-by-people-with-intellectual-disability)

²⁵ [Adjusting a mainstream weight management intervention for people with intellectual disabilities: a user centred approach - PMC \(nih.gov\)](https://pubmed.ncbi.nlm.nih.gov/32111111/)

²⁶ [Supporting people with learning disabilities to have a healthy diet and be active \(publishing.service.gov.uk\)](https://publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/444444)

²⁷ [Learning Disability - Health Inequalities Research | Mencap](https://www.mencap.org.uk/learning-disability-health-inequalities-research)

²⁸ [New report: "Lockdown on Loneliness" \(learningdisabilitytoday.co.uk\)](https://learningdisabilitytoday.co.uk/new-report-lockdown-on-loneliness/)

²⁹ [Smoking and People with an Intellectual Disability | Intellectual Disability and Health](https://www.bjld.org.uk/journal-articles/smoking-and-people-with-an-intellectual-disability)

³⁰ [Sexual health and people with learning difficulties factsheet.pdf \(hscni.net\)](https://www.hscni.net/sexual-health-and-people-with-learning-difficulties-factsheet.pdf)

Cancer is a leading underlying cause of death among people with learning disabilities and they are significantly less likely to receive NHS screening tests for cervical, breast and bowel cancer than those without a learning disability³¹. This is particularly concerning amongst women with learning disabilities, who are 45% less likely to be screened for cancer³².

People with learning disabilities are less likely to express pain and/or report changes in their physical appearance, which can lead to delays in diagnosis and symptom presentation³³. Other common barriers include invitations to cancer screenings not being in Easy Read, difficulties using appointment systems and accessing primary care services, and anxiety around attending screening tests.

Role of GP Services

The above has outlined the significant health inequalities people with learning disabilities can face, and emphasises the importance of GP services addressing and accommodating their needs.

Accessible Information

Under the Accessible Information Standard (2016) all NHS services are legally required to meet the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss³⁴. This includes:

- Being able to contact, and be contacted by, services in accessible ways
- Receiving information and correspondence in formats they can read and understand, including audio, braille, Easy Read or large print
- Being supported by a communication professional at appointments if this is needed
- Getting support from health and care staff to communicate, for example to lip-read or use a hearing aid

For people with learning disabilities, this often involves providing information in Easy Read. Easy Read information can give people with learning disabilities, choice, control and independence³⁵ and can help them to better understand health information. Despite this, research has shown that GP services are not always proactive in providing this information and/or in asking people with learning disabilities how they would like to be communicated with, creating another barrier in accessing health and care services.

Speaking slowly and clearly is also important for people with learning disabilities, however research has shown that both clinicians and receptionists can speak too quickly and use terminology which is difficult for people with learning disabilities to understand, again impacting their ability to access healthcare.

Reasonable Adjustments

The Equality Act (2010) states that the NHS must make reasonable adjustments to ensure that services are accessible to disabled people as well as everyone else³⁶. According to Mencap's Treat Me Well campaign, common reasonable adjustments people with learning disabilities could ask for include³⁷:

- Speaking clearly and using simple words

³¹ [Health_inequalities_cancer\(1\).pdf](#)

³² [NHS England – South West » Study shows only 1 in 4 women with learning disabilities attend cervical screening in the South West](#)

³³ [Health_inequality_cancer\(1\).pdf](#)

³⁴ [NHS England » Accessible Information Standard](#)

³⁵ [Why-Easy-Read-is-Important.pdf \(peoplefirstltd.com\)](#)

³⁶ [Reasonable adjustments: a legal duty - GOV.UK \(www.gov.uk\)](#)

³⁷ <https://www.mencap.org.uk/sites/default/files/2018-06/Treat%20me%20well%20top%2010%20reasonable%20adjustments.pdf>

- Providing longer, or “double” appointments
- Working with family members, support workers and carers whilst still directly involving and speaking to the person with a learning disability
- Flexibility with appointment times
- Ensuring there are no physical barriers for people using wheelchairs or with mobility issues
- Providing quieter places to wait
- Providing written information in Easy Read format
- Asking people with learning disabilities what they need rather than making assumptions

Although the following, and more, should be put in place, Mencap state that NHS services are not doing enough to ensure reasonable adjustments are implemented for people with learning disabilities, to enable them to access the healthcare they need.

Staff Training

Reasonable adjustments also means providing policies, procedures and staff training to ensure that services work equally well for people with learning disabilities³⁸. This has been further emphasised under the Health and Care Act (2022) which made it a legal requirement to provide staff training in learning disability and autism, including how to interact appropriately with autistic people and people who have a learning disability³⁹.

However, Mencap have found that one in four healthcare professionals have never been given training about learning disability, and that 50% of a lack of knowledge around learning disability might be contributing to the problem of avoidable deaths⁴⁰. Mencap argues that it is imperative that healthcare professionals receive more training on how to support and communicate with people with learning disabilities, and felt this would help people with learning disabilities receive better quality healthcare.

Annual Health Checks

People with learning disabilities over the age of 14 should be offered an Annual Health Check by their GP practice. Annual Health Checks aim to improve the health of people with learning disabilities by identifying unrecognised medical conditions and implementing preventative measures such as screenings, vaccinations and blood tests to safeguard the health of people with learning disabilities⁴¹.

A good quality Annual Health Check should take between 30 minutes and one hour, and include a thorough examination of an individual’s physical and mental health, as well as their lifestyle and general wellbeing. Annual Health Checks should also include the creation of a Health Action Plan, a personalised plan developed by the person with a learning disability and their practitioner, outlining how they are to stay healthy⁴².

However, from our [own research](#), and national literature, there are many people with learning disabilities who are not offered an Annual Health Check, and there are many who are only receiving a basic examination of their health and wellbeing.

³⁸ [Reasonable adjustments: a legal duty - GOV.UK \(www.gov.uk\)](#)

³⁹ [Training staff to support autistic people and people with a learning disability - Care Quality Commission \(cqc.org.uk\)](#)

⁴⁰ [2017.005.01 Campaign report digital.pdf \(mencap.org.uk\)](#)

⁴¹ [Annual health checks and people with learning disabilities - GOV.UK \(www.gov.uk\)](#)

⁴² [NICE impact people with a learning disability | Reviewing the impact of our guidance | Measuring the use of NICE guidance | Into practice | What we do | About | NICE](#)

Aims

The aims of this research include:

- To understand the barriers adults with a learning disability may face when accessing their GP practice.
- To explore whether GP services are providing reasonable adjustments to adults with a learning disability, and communicating in a way that is accessible to them.
- To explore whether adults with a learning disability feel supported and listened to by their GP practice.
- To investigate whether adults with a learning disability are supported by their GP practice to live a healthy lifestyle.
- To identify what additional support adults with a learning disability would like to receive from their GP practice to help them to live a healthy lifestyle.

Methodology

To achieve the aims of this engagement, we held in-depth one-to-one interviews and focus groups with adults with learning disabilities, as well as carers supporting an adult with a learning disability. We adopted a qualitative approach to enable us to understand the lived experience, views and perspectives of adults with a learning disability.

To promote the engagement and to ensure it was as accessible as possible, we created a number of Easy Read materials, including a flyer and promotional video which explained the purpose of the project and why it is important, how to get involved and how the information they share will be used and protected.

Participants could also choose the time and date of the engagement and whether it took place in-person, by telephone or on a video platform of their choice. Participants also had the option of bringing their support worker to help them share their experiences. This gave support workers an opportunity to share their views as well.

The engagement itself was made accessible through ensuring the questions used Easy Read language, and through using materials such as PowerPoint slides and interactive exercises to ensure that all participants could express their thoughts and feelings in a way that accommodated their communication needs and preferences.

The engagement period ran from 1st March to 2nd May 2023 and was shared with the NHS, Hertfordshire County Council, organisations supporting adults with learning disabilities and organisations supporting carers who look after an adult with a learning disability.

In total we heard from 15 people, which included two carers, four support workers, and nine adults with a learning disability.

Throughout this project we worked with Herts People First who provided excellent expertise and guidance on how to carry out the engagement, the creation of accessible promotional materials, and supported with the recruitment of participants.



Key Findings

Our findings demonstrate examples of best practice within some GP practices, however, concerningly, they also highlight the difficulties people with learning disabilities have faced in accessing their GP practice, and a lack of support around how to live a healthy lifestyle. Key issues include:

- Barriers in accessing their GP practice for an appointment, and the value of GP practices having a Care Coordinator to specifically support people with learning disabilities
- Lack of choice in regards to appointment type, time and date and choice of clinician
- Lack of understanding and awareness of accessibility and communication needs
- Lack of personalised, tailored information on living a healthy lifestyle
- Mixed experiences regarding Annual Health Checks, with concerns raised about the quality

**Please note that pseudonyms have been used throughout this report to protect the identify of our participants.*

Accessing GP Services

Making an Appointment

All of the participants primarily contact their GP practice by telephone, with all participants often having to wait a long time on the telephone before being able to speak to a receptionist. Occasionally, participants have visited their GP practice in-person with their carer to try and get the support they need.

“If I have to make an appointment, I use the telephone and you usually join the queue but you get through eventually. It takes a long time and I try to ring as early as I can in the morning, but it doesn’t make any difference.”

“It takes at least half an hour on the phone and sometimes up to an hour. We went one time to get an appointment quicker.”

“It can be quite a long time waiting on the phone or waiting for an appointment.”

It is important to note that all but one of the participants with a learning disability contacts their GP practice with the assistance of their carer or support worker. As such, participants are reliant on their carer or support worker to be with them when contacting their GP practice.

However, GP practice opening hours are often outside of their carer’s or support worker’s working hours. This is a significant barrier for people with learning disabilities and can exclude from being able to access GP services and from getting the care and support they need.

“Usually I’m not here at 8:00am in the morning to make appointments for him. More flexibility would be great because he likes to have support in making his appointments.”

“I’m only here 10:00am – 2:00pm and they say you have to ring at 8:00am in the morning or 2:00pm in the afternoon which doesn’t work for us because I can’t speak for her, so we struggle to get appointments.”

“It’s not easy a lot of the time because of the hours my support worker works. You know it’s harder to get through because they say you can only call within these certain times.”

Difficulties in getting through to their GP practice and in accessing an appointment has made some participants reluctant to contact their GP practice, despite feeling that they need medical attention.

“Sometimes we access the GP and sometimes we can’t because it is so difficult sometimes. I put it off which I shouldn’t be doing.”

“I have actively put that off because access and having a conversation with somebody that might not be taken in the right vein that’s my judgment I don’t know I think that is telling you a lot about how things have changed and how inaccessible it is now.”

Support workers and carers also felt that receptionists can be reluctant to offer appointments, meaning they need to be assertive to ensure the person they support is seen by a clinician.

“You can get through to the GP surgery and convince them to see people. But they’re still quite abrupt and reluctant to see people.”

This was emphasised by a couple of participants, who shared that they have to be assertive with receptionists in order to get their needs met.

“It makes it more difficult and it makes you feel that you hope you don’t have to speak to them that you get your regular receptionist. Yeah if it’s someone that doesn’t know me I get a bit worried.”

“If you have a particular concern whatever that concern is if you can’t get past the receptionist, it doesn’t make a difference. It doesn’t matter how urgent your concern is if they don’t pick up the phone, they can’t help you and I suppose there’s no special number if you have a disability or need extra support when you go online there’s no help pages if you needed to sign up there’s no page to help you.”

eConsult

As mentioned, all of the participants with a learning disability tend to contact their GP practice by telephone. None have used, or tried to use, eConsult to make an appointment or as a way of accessing their GP practice.

Carers and support workers in particular said that GP services are becoming too reliant on technology and as a result, are excluding people with learning disabilities.

“They encourage you to use online eConsult. How someone with special needs is meant to be able to use eConsult is beyond a joke. My son would not even be able to access it. This is a completely inaccessible system for people with learning disabilities.”

“I’m concerned it’s not just the NHS it’s everywhere going online and I don’t have a problem with it but some people don’t know how to use it.”

Care Coordinators: Example of Best Practice

Ben, Becky and Amy* are all registered with a Purple Star accredited GP practice. At their GP practices, they have a Care Coordinator who they can contact if they need support in accessing GP services.

“We met a Care Coordinator who we can text or call if we need an appointment.”

The Care Coordinator will support them in making appointments, and will also work with them to ensure the appointment is at an appropriate time and with the clinician of their choice. Amy’s Care Coordinator will also meet her outside of the GP practice and will accompany her to any appointments she has, including dental appointments.

“If I say to them I want my doctor then I see that doctor. They don’t just give me Tom, Dick or Harry.”

“She comes with me to appointments and she’ll meet me outside so I don’t have to sit in a busy waiting room and get nervous with everybody watching me and how to sign-in.”

Ben, Becky and Amy used to find it very difficult to access their GP practice, so having a Care Coordinator has been invaluable.

“I am so happy that the Care Coordinator can text me or ring me. Or I can ring them. Now I don’t have to ring the GP surgery I just communicate with that person if I need to.”

Support workers also praised this initiative and felt that this support for people with learning disabilities should be offered at every GP practice.

“It’s brilliant. We found out about the Care Coordinators recently in Stevenage and our recommendation is to get a Care Coordinator working just with people with learning disabilities at every GP practice.”

However, it is important to note that Becky and Ben only found out about the Care Coordinator at their GP practice by attending their GP practice’s Patient Participation Group. Ben and Becky are concerned that other people with learning disabilities will be unaware that this support exists.

“It was purely because we are members of the Patient Participation Group. Otherwise we wouldn’t have known about this person’s existence. And so I’m very worried that people with learning disabilities in Hertfordshire will not know about it, it’s like winning the lottery whether you know or don’t know.”

They are also concerned that Care Coordinators only work within the GP practice’s opening hours, meaning that they still have to rely on out-of-hours support, which they have had difficulty accessing in the past.

“I think if the Care Coordinator is operating in what I would call normal working hours then essentially we’ve got access to support. But out of normal working hours we are on our own.”

Choice

Appointment Preference

All participants prefer to have a face-to-face appointment with a clinician rather than by telephone or video call. Having an appointment face-to-face was important to people with learning disabilities, with many emphasising that this makes them feel more comfortable and an easier way of communicating their health needs and concerns.

“I’d rather be seen face-to-face with a doctor, rather than him ringing me up saying you’ve got this, you’ve got that.”

“I like face-to-face with a chat with the doctor in the surgery itself.”

“I would like to see a doctor in-person. I find this is better for me because they can understand me better.”

Positively, most participants said that they can often see a clinician face-to-face if needed and/or requested. Some carers and support workers also acknowledged that the GP practice is accommodating in providing home visits to meet the person they care for’s needs and preferences.

“(Amy) has said very clearly it has to be face to face and they have always done that.”

“He can’t actually attend GP appointments at the surgery, his challenging behaviour is so much that is a real problem, and the GP overtime has understood this so will visit him in his own home. So that’s really positive. They do accommodate him.”

However, a couple of participants have faced difficulties in accessing face-to-face appointments, with receptionists not acknowledging their choice and why this type of appointment is important for them.

“It’s not always easy to get a face-to-face appointment. I had a very bad cough and cold and asked if I could see someone. I had it for two days and didn’t hear so I rang again on the Monday and had to speak to someone over the phone.”

“Before COVID I used to go in. At the moment they ring me up now on the telephone. I can’t remember when I last went in. I’d rather go in.”

Participants also emphasised that they would or have struggled to have an appointment with a clinician by telephone or video call. Reasons included difficulties using and accessing online technology and difficulties hearing and communicating.

“They need to hold the phone close. I had an Annual Health Check and the woman was holding the phone away from her and from that moment I refused telephone calls because of people holding the phone too far away and I can’t hear them.”

“I like seeing the doctor in person. I didn’t like being on Zoom speaking to them. They would talk too fast or sometimes it would freeze.”

“A lot of people use Teams a lot which I don’t know how to use. It’s not an option, I’m not an IT person. I don’t know enough, I can’t set my computer up.”

In addition, some participants shared that having an appointment by telephone or video call can make them feel very anxious. It also means a clinician cannot physically examine them, which can also increase their anxiety.

“Normally I get quite anxious when it’s by phone.”

“Sometimes I want reassurance so it is better to see someone. I did find it hard during COVID when you just saw someone on Zoom. If you can’t physically see the problem, how s a computer screen going to help if you can’t touch the area that’s painful.”

Receiving test results and information by telephone or video call can also be difficult for people with learning disabilities, causing unnecessary concern and anxiety. One participant, Harry*, received a telephone call from a clinician to talk to him about his test results. Harry does not like speaking to clinicians over the telephone as this can make hm feel very anxious and distressed. Feeling overwhelmed, Harry had a panic attack and had to call the ambulance for help.

“About five months ago, Harry took a call from one of the doctors about his results and it got Harry worrying so much it led to Harry calling an ambulance to take him to hospital because Harry suffers from anxiety and he had a panic attack so I think it was poorly handled in that respect. I think they need to be more mindful when they’re talking to people like Harry or someone with a disability. Sometimes it can be too much what they’re saying and the information is quite confusing.”

Carers and support workers also shared that the person they care for would need, or prefer, to be supported during their appointment, which is much easier to accommodate for when the appointment is face-to-face. They also stressed the importance of clinicians seeing people with learning disabilities face-to-face so they can be physically examined. They felt this is particularly important given that people with learning disabilities can find it difficult to communicate their needs, pain and symptoms.

“If it’s only a phone call you can’t see whether they have lost weight, you can’t see if they’re anxious, it has to be face-to-face. How can you diagnose a person with a learning disability or get to the bottom of what is wrong? My son can’t articulate very well what his issues are.”

Choice of Time and Date

When booking an appointment, most participants are given a time and date and are not able to choose this for themselves, which some participants can find difficult to fit around their own routine, schedule and activities. This lack of flexibility and choice also means that some participants have to wait several weeks before seeing a clinician.

“He would find it very difficult on the phone. We have done video, but I’ve been there. I’m his main carer, how is he going to access this when I’m not here because he couldn’t access that video call.”

“They usually tell us a time and a date and sometimes we have to work around that or ask for a particular day and then sometimes that can be weeks away which isn’t ideal.”

“They give you a time and date and sometimes I’m busy, I’m working. I only work twice a week but I’ve got to work all of that out.”

Most participants prefer to have their carer or support worker accompany them at their appointments. As such, being able to choose a date and time when their carer or support worker will be available to attend with them was very important.

However, some GP practices do not always accommodate this. For example, Paul* and Mia* said that despite telling their GP practice that they can only attend appointments on the days their support worker is with them, their GP practices continually book appointments on dates and times that they cannot attend.

“If we say to them I’ve got no one to support me, they should say that’s fine we’ll find another time, they make sure people have got their support. They say we can do this time or that time but no one is there to support me at that time.”

“I tell them that I’ve got no one with me to help me, can we do another day? So they say can you do a day like tomorrow. I say we can only do it at this time. I don’t think people understand that I need support.”

Support workers and carers find this equally frustrating and emphasised that this barrier can prevent people with learning disabilities from receiving medical attention in a timely manner.

“I support (Harry) on Thursdays so he saves any letter he gets through the week. If he gets any then I try and get appointments for him when I’m with him on a Thursday. That’s the only day he gets support so it would be problematic to rearrange appointments. I can’t always be flexible because I have other clients as well so it can be problematic.”

“It’s quite rare for him to get an appointment. It’s quite difficult to get one on a day I’m here.”

However, some participants said that their GP practice will try to be flexible where possible and will work with them to find a date and time that is suitable.

“Sometimes they tell me when the appointment is. I can tell them I can’t make it and they will change it.”

When having a telephone appointment, participants shared that they are given a large time window rather than a specific time slot. Participants said that they can find this very difficult as their support worker or carer might not be with them to help and/or they might be busy when the clinician calls.

“Sometimes they give a general time when they phone like a time between 12:00pm and 2:00pm so we want to do something and not wait about. So they have phoned us when we’re out and about and you can’t guarantee good reception or privacy. So any feedback would be to give more precise times when they contact you. Rather than a two hour slot, maybe a 20 minute slot so you can be somewhere quiet and take the call.”

“It’s when they do it and I have no one here I say to them can you ring 10–12 on a Tuesday or 9:30–11:30 on a Thursday when that time comes you have gone, and they ring. They sometimes ring later when there’s no one there to help.”

Choice in Clinician

Most participants prefer to see the same GP or nurse. This continuity is important to people with learning disabilities and helps them to build communication, trust and a rapport. It also means that they do not have to keep repeating their medical history, which they can find frustrating.

““You have to see whose there and not your regular GP which makes it difficult. Because I’m epileptic and I have a physical disability which is invisible I like to see my GP. She knows everything about me but nobody else does and that’s the problem.”

“I would like it if my regular GP could see me at least two or three times a year. I don’t use my surgery that much to be honest. I would have seen them about the pain down below my waist. I didn’t ring them because I only want to see my GP who I know.”

“You’re having to go through all your history to fill them in and it takes up time. And then when you see another person you have to go through the same thing all over again. If I see my GP then this doesn’t happen.”

However, most participants will often have to wait several weeks if they want to see the clinician of their choice.

“They ask if you want to see a particular doctor, but you could be waiting for around three weeks. I could see the others face-to-face that were available, but I prefer to have my doctor.”

“We have a really good GP. But it takes about two or three weeks until we can actually see our GP.”

Seeing the same clinician is important to carers and support workers too, who also appreciate the familiarity and assurance that the clinician has a good understanding of the person they care for's health needs.

“If we get to see the doctor who has known him all his life then he is so well looked after, they have known him since a baby and we are very happy there are still GPs who know him, but it's an if.”

Communication

Attitudes of Clinicians

The majority of clinicians shared how “nice”, “thoughtful” and “kind” clinicians are. Participants particularly appreciate clinicians who are patient and take the time to listen.

“They listen to you.”

“The doctor has been good at listening to our advice on how to support him but also treating him like a human being in his own right.”

“They are fantastic, they are really switched on, they are really good at listening. We have to tell them things like use simple words, no chatter, don’t make any noise, things like that, and they are brilliant with all that and listen to us.”

However, a few participants recounted experiences in which clinicians had a lack of understanding and awareness of their needs and in some cases, treated them poorly.

“The person with a learning disability knows that they’re not going to be listened to, they’re not going to be taken seriously whatever problem they’ve got, they know what problem is not going to get solved. We have to find our own coping strategies because we are fed up, angry and all the bad language you can put together of not being believed by healthcare professionals and this starts in GP surgeries.”

One participant, Claire* said that clinicians will often speak to her support worker about her health, even though she is in the room, which she described as “horrible” and “unkind.”

“It’s not kind and it’s not appropriate to talk to someone about you when you’re right in front of the doctor. I think hello? Hello I’m here. You don’t need to ask them, ask me. It makes me feel horrible and it’s unkind.”

Other participants shared similar experiences, emphasising that clinicians will often speak to their carer or support worker, rather than the person with a learning disability, which makes them feel ignored and disempowered. If someone with a learning disability is non-verbal, support workers noted that they will often not be spoken to at all.

“People who are non-verbal are bypassed completely.”

“Sometimes they don’t speak to the person. If there is staff there they’ll start talking to the staff.”

“The system will often talk to parents first. They are very good at listening to parents. I’m not saying the views of parents aren’t important, what I am saying, when you go to the GP surgery or you access the GP, the system is not good at listening to the voices and health needs of people with learning disabilities independently of their parents or whoever happens to be in the supporting role.”

Communicating with Receptionists

Participants shared that they often have trouble communicating with receptionists and in some cases, were treated very poorly. For example, one participant, Becky* is told by receptionists at her GP practice that they cannot understand her and to “hurry up” when she is speaking, which Becky finds distressing and disrespectful.

“If I ring up they can’t hear you and there are too many people in the background and they say I can’t understand you, they say I don’t understand you. They were saying hurry up. I feel like saying to them sorry I’ve got a disability and didn’t choose to have a disability, I was born with a disability, how can I wipe it away.”

On a separate occasion, Becky visited her GP practice in-person to speak to a receptionist and the receptionist called for her to be removed which Becky found offensive and inappropriate.

“I was at the GP surgery and they opened the door as I was talking and shouted “can someone come and get her!” and they were calling someone to get me out of the reception.”

Participants Ben*, Daniel* and Fran* have had receptionists question whether they have a learning disability on several occasions, which they all find insensitive and rude, and often prevents them from getting the care and support they need.

“Sometimes, maybe because of the way I come across, I’ve been asked, do you have a learning disability?”

“I have to explain to them I have a learning disability. I had to keep saying I have a learning disability and I’m on the learning disability register.”

“I’m quite high functioning so they don’t see me as disabled.”

In contrast, a couple of participants have had a positive experience when speaking with receptionists. For these participants, there is a receptionist at their GP practice who knows them well and knows how to communicate with them.

“There’s one who knows me on reception and is good. The others don’t know me as well so it depends who I get.”

Accessible Information and Reasonable Adjustments

Reasonable Adjustments

Under the Equality Act (2010) the NHS must ensure that services are accessible to disabled people, including people with learning disabilities. This is called making reasonable adjustments⁴³.

However, some participants face physical and practical barriers when accessing their GP practice, with a number emphasising that they find waiting rooms uncomfortable, the sign-in process difficult to use, and the GP practice too busy, all of which intensifies feelings of anxiety and distress.

“You go to the appointment and you sit and you wait and you’ve got the time but it takes a long time and I’m sat in the waiting room for a long time which I can find hard.”

“I don’t like going to the doctors when it’s busy that makes me very anxious.”

One participant, Claire* has Cerebral Palsy and uses an electric wheelchair. Claire finds it difficult to visit her GP practice because it is not physically accessible for her. Fortunately, Claire’s GP practice is often very accommodating in providing home visits when she needs medical attention.

“I would love to go and be independent but it is a bit hard for me because going to the GP surgery you’ve got to think of the roads. For me that’s quite difficult because I’ve got to think about my wheelchair about getting up the roads. I have been to the GP surgery but I would prefer to avoid it and have someone come out to me. It’s hard for me to get to the surgery because of my electric wheelchair and the GP surgery does not have enough room for my electric wheelchair so it is hard to be there.”

Carers expressed that they have to constantly “fight” to get their child’s basic needs met and to ensure that the reasonable adjustments their child needs are implemented.

“I have to repeat this information every time and negotiate that every time. Even though it’s on his file that message doesn’t get through.”

“You are continually fighting for different things for them. You have to fight for things and sometimes you’re not listened to.”

⁴³ <https://www.gov.uk/government/collections/reasonable-adjustments-for-people-with-a-learning-disability>

For example, one carer, Nicole* cares for their adult child with a severe learning disability. Her child can only receive home visits which must be at a specific time to enable her child to be sedated beforehand. Despite this information being on her child's medical records, Nicole has to repeatedly remind the GP practice of this information and why it is so important.

"I would say 80-90% of the time I have to explain the situation from scratch, and it doesn't particularly give us any support of fast track or any preferential access. I think the reasonable adjustments we have now, I think that's taken about 5 or 8 years to get right, it's just been a real fight. I don't think it's an admin error I think it's a cultural error, unless you ask, you're not going to be offered."

Accessible Information

Under the Accessible Information Standard (2016) the NHS must ensure that it supports and addresses the communication needs and preferences of people with disabilities, impairment and/or sensory loss⁴⁴.

Providing information in an Easy Read format can help people with learning disabilities understand information more easily. However, this engagement found that some participants have never received information in Easy Read and in some cases, have been asked what Easy Read information is.

"When we ask for accessible information, the standard response we get is I don't know where it is and where to go on the system. They say there isn't any."

"Often, we are told "what is Easy Read?" the only accessible information that we've received is from Herts People First."

"I've never had an Easy Read anything in my life."

One participant, Daniel* has a mild learning disability. Daniel feels that because of this, he is never given information in Easy Read or an alternative format. Despite emphasising that he needs information in a different format, Daniel has never received this. As a result, Daniel can find it very difficult to get the support he needs.

"I can't believe that I'm the only person in the world who has said "can I have it in a different format?" if you have a disability, you have the right to choose it in a different format that disabled people can actually read. It's just one size fits all. If you can't read the stuff, you just have to deal with that."

It is also important that clinicians communicate with people with learning disabilities in a way that is accessible to them. However, some participants said that clinicians speak too fast and use words that

⁴⁴ <https://www.england.nhs.uk/about/equality/equality-hub/patient-equalities-programme/equality-frameworks-and-information-standards/accessibleinfo/>

they find difficult to understand. Participants tended to have a more positive experience when speaking to a clinician they know well.

“I speak slowly and quietly and sometimes they don’t wait for me to answer and sometimes they talk too quickly which is hard.”

“Sometimes they speak too fast.”

“They try to speak slowly but it depends on who. I know there are three or four GPs that are very good, then I would say that there are others who don’t have a clue.”

Support in Living a Healthy Lifestyle

Healthy Eating and Weight Management

Positively, most participants with a learning disability said that a clinician has spoken to them about healthy eating, weight management and the associated health risks of being overweight and not eating a balanced diet.

“The reason why we choose to see our GP is because the way in which Becky communicates, the GP gets it. The other doctors, one comes across impatient and the other one, although professional and kind, I think they feel a little out of in-depth.”

“She sat down and told us what to eat and not what to eat. What to cut out and what exercises to do.”

“We do get advice or guidance about healthy diet, high fibre diet, exercise.”

“They told me if you’re overweight you can get all sorts of illnesses like diabetes and stuff and that you are best to keep yourself healthy in the long run, and if you’re not overweight you can do more things like sports and stuff.”

However, almost all of the participants would like more information about how they can eat healthy. Some participants specified that they would like Easy Read information which they can take home, as they find it difficult to remember the information and advice given during the appointment, particularly if they attended without their carer or support worker.

“There could be more information and leaflets. There should be more Easy Read information for them about staying healthy. There’s not been a lot of that.”

“I would like more information about staying healthy and about food.”

“I’d like more information, like your fruits and vegetables and everything like that.”

“There is a problem in regard to remembering the advice you’ve been given because you haven’t got the support to remind you.”

Some participants shared that although they have received information about healthy eating, they would like more guidance and support on how to put this information into practice, for example through the provision of meal plans and simple recipes.

“A person can give healthy food information or a sheet where it says do this but what we don’t actually have the support to implement that.”

“I would like information on how to cook nutritious things. I want to know how to cook them like pasta or toad in the hole, how you actually do it. They could say here’s what we think you could have and get you to try these recipes.”

In addition, a few participants feel confident in their knowledge about healthy eating, but would like more information on nutrition and how to maintain their weight.

“We have the Slimming World microwave meals but I read that they are not good for nutrition so we need information about the types of foods to cook.”

“The information I would like is about nutrition, that’s a big thing for me because I have lost a lot of weight. I was 24 stone and now I’m 11 stone. I want information on nutrition because I’ve lost this weight but I want information on how I keep my weight down because that’s what I’m finding difficult. I’ve got off my takeaway meals that was the hardest part, now I’ve got off that I’m struggling with other things because I’ve done everything I can.”

Other participants would like to have more regular conversations about healthy eating with a clinician and for this advice to be given face-to-face, rather than through leaflets or online resources.

“I suppose he knows where to find the information if he wants to but it would be nice to hear it from a healthcare professional instead of reading it on a website.”

“I think that speaking to someone about nutrition would be better for me.”

A few participants have been referred to weight loss programmes such as Slimming World and Weight Watchers. However, not all participants found this helpful as the programmes are not tailored to people with learning disabilities. As such, they are often not accessible, and the information given can be difficult for them to understand.

“It’s not personalised. None of it is personalised.”

One participant, Becky* asked if the Purple Star Strategy could educate Weight Watchers on how to support people with learning disabilities but she was told this could not happen.

“When Becky was overweight the standard referral was to Weight Watchers. Because of the experiences Becky had in regards to the programme, Becky recommended that the Purple Star Strategy could talk to Weight Watchers about health for people with learning disabilities. But Becky was told that couldn’t happen because Weight Watchers is a private company. If GPs want to refer people and help people lose weight, eat well, then these private companies aren’t right. They need learning disability awareness.”

Support workers also mentioned that when a referral is made to a weight loss programme, there is no follow-up from a clinician to see whether they are attending and/or how they are getting on.

“There’s no follow-up. They’ll give a referral to Weight Watchers or Slimming World, whatever it happens to be, whether you turn up or not it doesn’t matter so it’s not that great.”

It is also important to note that support workers and carers play a significant role in helping people with learning disabilities to stay healthy. It is often the support worker or carer who provides the information and explains how in practice they can eat a balanced diet. Without this support, participants would perhaps need more support from clinicians.

“My key worker has been helping me to lose weight.”

“The support worker does meal prep and sorts the portion sizes and makes sure it is healthy.”

“We try to eat healthy everyday. They have shopping lists and we try to work out a menu plan and we change up the meals. We’ve got noticeboards about healthy stuff and a folder all about healthy cooking.”

Exercise

Most participants have received information from a clinician about the importance of exercise and keeping active.

“Got to do 35 minutes a day of fitness and they said to me you’ve got to walk or do something active once a day to keep yourself fit and stuff.”

“They gave me information stuff about walking and stuff, which I didn’t mind because walking is quite easy for me.”

However, some participants said they would like further information about how to stay active and practical information and advice about the types of exercises they should be doing.

“I did try to do exercise but it’s a tricky one for me. I would like a doctor or nurse to tell me what more can do.”

“Before COVID I used to walk up and down in our bungalow. Now if you ask me now can you go again, walking in your bungalow, that confidence from before COVID has gone. I would need someone to help me [rebuild] that.”

“How to keep fit. What exercises I could be doing and when.”

One participant, Becky* was referred to a clinician to a local gym to help her with her mobility and to lose weight. However, the gym was not tailored to people with learning disabilities and had no awareness or understanding of how to support people with learning disabilities. This was inappropriate for Becky and meant she had some challenging experiences when attending.

“There was a link to the gym for Becky to go to but that’s also tied in with people who have heart conditions, it’s for everybody, not just people with learning disabilities. Because it’s not specific, that meant that Becky actually had some unexpected and difficult experiences and had to come into contact with people who aren’t learning disability friendly.”

Again, it is important to highlight that carers and support workers play a key part in supporting participants to stay active and exercise. Those without this support might face more difficulty and need greater support from clinicians.

“My key workers help me a lot with keeping my weight down and doing exercises.”

Mental Health

It is important that clinicians talk to people with learning disabilities about their mental health as well as their physical health. Some participants have had a clinician discuss their mental health and wellbeing, while others have not. However, most participants had only been asked about their mental health during their Annual Health Check, rather than during routine appointments and check-ups.

“Yes they did...there were pictures and stuff like ticks and smiley faces and stuff.”

“It was part of their Annual Health Check to talk about feelings. The doctors and nurses don’t ask in general appointments though.”

“They have a few times but not lately.”

Most participants were unsure whether they would like mental health support from a clinician, with many stated that they feel supported by their regular clubs, activities and groups.

“I go to my Soul class so I’m seeing and speaking to people. Might be helpful for others though.”

“I’m not sure, I’m quite happy. Maybe they should ask me though.”

One carer, Cath*, said a clinician has not talked about mental health with her son, but felt it would be valuable for her son to be told that his emotions are valid and not to blame himself for other people’s emotions.

“I think it’s about him understanding what sometimes not being happy is ok and sometimes not saying the right thing is ok.”

One participant, Ben*, was referred by a clinician to take part in an online course to support with his mental health. The online course was not personalised for people with learning disabilities and was not accessible to Ben. Ben felt he was referred to this course because he has a mild learning disability and that the clinician made the assumption that he would be able to understand, which he felt was inappropriate.

“I was referred to a system which was this course online which didn’t work. In my case, the way in which I was assessed with face-to-face but someone made the decision to put me on a course which was online. The actual information I couldn’t take it and use it and I couldn’t read it.”

Another participant, Becky* spoke to a clinician about her anxiety. Becky received some information to support her, but it was not given in Easy Read, so she could not understand it.

“Becky has an anxiety disorder and the information Becky received gave a bit of information but wasn’t in Easy Read.”

Positively, one respondent, Fran* told a clinician that she was feeling lonely. The clinician referred Fran to a social prescriber who has been working with Fran to find some groups, clubs and activities.

“Hopefully she will find something for me. I would like someone to come to me. The time I need it most is around Christmas because on Christmas Day I get very lonely and depressed, I have ended up crying and saying nobody loves me. That has happened once or twice. Especially Christmas Day. I can manage my depression very well otherwise through the year. At Christmas time everything is closed down. There’s nowhere to go. In Hertfordshire there’s not much around on Christmas day.”

Lifestyle and Screenings

Most participants have had their weight, height and blood pressure checked by a clinician. However, the regularity of this differed amongst participants.

“They check it but not every time.”

“I don’t think I’ve been weighed or had my height checked for over 10 years.”

“Yeah, [the GP] checks my weight and my height and my blood pressure regularly.”

The majority of participants have not been asked about whether they drink alcohol, smoke or use drugs. Most felt that because they do not engage in this behaviour, they do not need to speak to a clinician about it.

“Yeah, they ask and I say on special occasions I drink alcohol.”

“I will never smoke. You will never ever get me into smoking or alcohol. I don’t like the taste of alcohol. I do take drugs, but they are not party drugs.”

“They’ve asked me loads of questions but the answer is no, they haven’t asked about that.”

“No they haven’t asked, I don’t smoke, I don’t drink and I don’t take drugs apart from prescriptions.”

One participant, Harry* used to drink an excessive amount of alcohol. Although Harry has stopped drinking, he said that clinicians do not ask him about this alcohol intake, despite his history.

"I was in Lister Hospital; I was in the Drugs and Alcohol ward. She said what is that above your liver. I said I haven't got a clue. She said you'll be dead in 2 years; I didn't know I was killing myself. This was awhile ago. I had to make the decision to quit. They don't ask me about that."

Support workers also felt that clinicians should have more regular conversations with people with learning disabilities about the prescription drugs they are taking to ensure they have the right dose and are taking the medication correctly.

"It's important that doctors talk to them about the drugs they take because a lot of them are more powerful!"

In regard to sexual health, most participants have not had a clinician talk to them about this, although most felt that they did not need this information. Clinicians have spoken to Ben* and Becky* about sexual health, but they felt the information given needs to be updated.

"Based on what we were told, it needs a radical overhaul. It's coming from the starting point of the 80s and 90s and what to tell disabled people, if I put it like that."

Concerningly, the majority of participants said that a clinician has not discussed cancer screenings with them and how to check parts of their body for any lumps, discolouration and irritation. Some participants had no awareness and asked what cancer screenings were.

"I have cancer in my family, but I haven't been spoken to directly by doctors. So the answer is no."

"What's a cancer screening?"

"Have I been checked?"

"I haven't been told about any screenings."

Some participants were anxious about bowel cancer screenings and felt unsupported by carrying out the home test kit. One support worker shared that some people with learning disabilities can find it frightening to receive a bowel cancer screening test in the post, as they often do not understand the instructions and do not know who to ask for help.

"The thing I'm not good at is doing the bowel cancer screening, that is something I fall down on."

“They find it very frightening, they don’t know how to do it and they don’t know who to ask. So, some people do come to me and I try to get the learning disability nurse involved.”

Positively, one participant, Fran* had a learning disability nurse support her during their cervical cancer screening and helped them to feel more relaxed.

“The learning disability nurse that day told me I could get a tablet that would relax me. It meant I wasn’t pulling against the pain which was making it more painful. It worked for me.”

In terms of bowel and urine, some participants said a clinician has spoken to them about what their bowels and urine should look like, while others have received this information from elsewhere, such as Learning Disability Forums and Coproduction Board meetings.

“They get the examples out at the County Council meetings sometimes and show us all.”

“They always ask what colour is your wee and poo and if there has ever been blood in your poo.”

In contrast, one carer, Cath* felt that GP services need to prioritise ensuring that people with learning disabilities are accessing care and having their basic health needs met, before focusing on providing support for living a healthy lifestyle.

“How can they have a healthy lifestyle when their underlying health needs that they were born with are not being monitored properly? GPs should know a healthy lifestyle should be about sorting what their main issues are, otherwise, they can’t access a healthy lifestyle can they?”

Annual Health Checks

Most participants have had an Annual Health Check, with some sharing that they had a good experience and praised clinicians for carrying out a thorough examination of their health and wellbeing and for their communication skills.

"It was a lady, and she was kind and patient."

"I had a really good time with my nurse. She's really nice."

"I would say 2 or 3 annual health checks, the doctor has been good at listening to our advice on how to support him but also treating him as a human being in his own right."

Annual Health Checks: Example of Best Practice

We spoke to a group of participants who live in a residential home. A female and male GP visited the residential home to carry out an Annual Health Check with each resident.

"We had a male doctor and a female doctor come in and we split the male doctor with the chaps and the female doctor with the ladies."

The participants received a thorough examination of their physical and mental health, and were asked questions about their general health and lifestyle.

"I told him about my mental health. I had a bit of a bad day and he got one of the mental health doctors to come and see me. He did my blood pressure too and did a blood test and he told me about losing weight. He told me about my relationship and talked to me about sex and he asked about smoking and he asked about drink."

The support workers noted that they spent a lot of time with each resident before the Annual Health Check to prepare them and to complete the relevant paperwork.

"We sat down with all the forms and we sat and talked about it at a meeting didn't we? Then you spent time with your key worker one-to-one to add more bits to the forms. So that helped the doctors focus on what to ask and helped to make the experience better."

Although a positive experience, one support worker felt that the examinations and questions asked during an Annual Health Check should happen throughout the year.

"Often all the questions happen at the Annual Health Check rather than throughout the year which would be better."

Some participants had a negative experience at their Annual Health Check, including receiving a short appointment (20–40 minutes), a basic examination of their physical and mental health, and having the appointment over the telephone rather than face-to-face. A few examples have been outlined below.

Ben* and Becky* had their Annual Health Check together but were only given 20 minutes between the two of them, when an Annual Health Check should take between 30 minutes to an hour per person. Part of the Annual Health Check was also carried out by telephone, which Ben felt was inappropriate.

“We get 20 minutes between us. The time runs out fast. The last time we did our Annual Health Check we had a phone call from someone and they rattled through a very long list of questions. The purpose of the call was to give the doctor the information they would need beforehand because they wouldn’t be able to ask them all face-to-face. I’m worried that if I’m struggling to cope with a phone call like that, I’m worried about other people with learning disabilities who can’t articulate as well. I left the phone call burnt out.”

Paul* has only ever had an Annual Health Check completed by telephone. Not only is this inappropriate as a physical examination should be carried out, but Paul also often becomes anxious and distressed during telephone appointments.

“The only Annual Health Check Paul has done has been over the phone, not in person.”

Fran* did not have her Annual Health Check with her regular nurse, and the clinician she had did not carry out a thorough examination of her physical and mental health. The clinician also did not ask Fran many questions about her health and lifestyle, and the appointment only took between 20 and 25 minutes. Fran also found it hard to communicate with the clinician because he was looking at the computer, rather than her.

“I didn’t get my regular nurse...it was a chap and basically he didn’t ask any of the questions around cancer, about cancer checks, or anything which was a bit off and I had to ask him. We went through the regular blood test...he didn’t weigh me. [The appointment] wasn’t very long, like 20 minutes to 25 minutes, it wasn’t as long as normal. He slipped right behind on all the questions he is supposed to ask me. He was looking at the computer and talking to the computer...I need the person to look at me so I can lip read.”

Fran also shared that her GP practice has not been using the term “Annual Health Checks” when corresponding with her, which she has found very confusing.

“The doctors use the phrase “people with long term conditions” instead of “Annual Health Checks” and also calling it other things as well. They are not using the term “Annual Health Checks” which everybody knows. When I rang up after I got a text, because the text said people with long term conditions, it was only through me asking, is this anything to do with Annual Health Checks. I could have ignored it. We’ve all been trained to use the term “Annual Health Check” and to use another term isn’t helpful to anyone, me, you, no-one!”

Mia* received a basic examination at her last Annual Health Check and felt that the clinician was inpatient and did not take enough time to discuss her health with her.

“It weren’t very good…… I don’t think they have done what they call a full annual health check…… I haven’t heard of anyone that has actually had a full check.”

A couple of participants have never had an Annual Health Check or have not had an Annual Health Check in several years.

“I found out about three or four months ago that as a young adult with a learning disability he should have a general check-up yearly. I’ll tell you that’s not happened and it hasn’t been promoted at any stage ever.”

“I can’t remember when my last Annual Health Check was. They don’t send letters about them to me. I don’t know.”

One participant, Daniel*, has not had an Annual Health Check for a few years. At his last Annual Health Check, the clinician did not provide Daniel with Easy Read information, meaning that Daniel found it difficult to engage in the discussion and to follow-up on the information he was given.

“I once had an Annual Health Check two or three years ago. It was a bit hard to read. It all goes back to communication, so there’s no point in the doctor printing me off stuff to go home and read if I can’t read it, if it’s not in a format that’s accessible. I couldn’t read it and I couldn’t ask questions.”

Conclusion

Overall, these findings raise concerns regarding the level of access people with learning disabilities have to GP services and the quality they are receiving. In terms of access, as with the general population, participants faced barriers such as delays in getting through to their GP practice and long waiting times for appointments. However, this engagement found that these challenges are clearly exacerbated for people with learning disabilities. Examples included restricted contact hours and lack of flexibility in appointments times preventing participants from accessing their GP practice, particularly as most participants are reliant on their support worker or carer being who available to help them. Best practice was shown amongst participants who had a Care Coordinator who could be their point of contact and support them in accessing GP services.

In terms of quality of care, choice was a significant factor, with many participants not able to choose the type of appointment they had, the time and date of the appointment, and the clinician they saw. Face-to-face appointments, flexibility in appointments times, and seeing their usual clinician was very important to participants, however in many cases, these needs were not accommodated.

Communication was another concern, with many participants recounting incidents in which clinicians and/or receptionists treated them poorly. This included clinicians speaking to their support worker or carer instead of directly to them, questioning whether somebody had a learning disability, and treating participants with disrespect.

Many respondents also did not receive information in Easy Read and were not communicated with in a way that was accessible to them. Reasonable adjustments were often not met, despite this being recorded on their medical records and repeatedly requested.

Positively, most participants felt supported by clinicians in living a healthy lifestyle, with many having received information on healthy eating and exercise. However, they felt that clinicians could provide more information on how to put this advice into practice, and to ensure that any support provided is personalised to meet their individual needs. It was also clear the clinicians need to do more to ensure that cancer screenings and mental health are discussed with people with learning disabilities.

In terms of Annual Health Checks, participants had a mixed experience, with some receiving a thorough examination of their physical and mental health, and others only having a basic examination and a short appointment, which did not sufficiently address all of their health needs.

Recommendations

Based on the findings outlined in this report, it is recommended that the Hertfordshire and West Essex ICB Primary Care Board should encourage GP practices to take forward the following recommendations.

Access

1. GP practices to continue improving telephone systems to reduce delays and waiting times for patients.
2. GP practices to allow people with learning disabilities to contact their GP practice for a same day appointment outside of the 8:00am timeframe. This will allow people with learning disabilities to contact their GP practice when their carer or support worker is with them.
3. GP practices to have a Care Coordinator or a primary point of contact specifically to support people with learning disabilities in accessing their GP practice.
 - If a GP practice has this support available, they should ensure that people with learning disabilities registered at their GP practice are made aware of this.

Choice

4. GP practices to allow people with learning disabilities to choose the type of appointment they have, and offering face-to-face appointments in the first instance.
5. GP practices to ensure that with learning disabilities can choose the time and date of their appointment, so they can make sure this is when their carer or support worker can accompany them.
6. If a telephone appointment is booked, a specific time slot is to be given rather than a large time window. This will enable people with learning disabilities to ensure they are (a) available to take the call (b) have their carer or support worker with them (c) be in a quiet area to have the consultation.
7. GP practices to ensure that people with learning disabilities can choose to see their usual clinician to provide continuity of care and familiarity.

Accessibility

8. Under the Health and Social Care Act (2010) GP practices are to be proactive in asking whether someone with a learning disability needs, or would like, any reasonable adjustments.
 - If reasonable adjustments are requested, they are to be recorded on the patient's medical records and implemented accordingly.
9. Under the Accessible Information Standards (2016) GP practices are to be proactive in ensuring that people with learning disabilities are communicated with in a way that is accessible to them.

10. GP practices to also ensure that information is provided in a range of formats, including Easy Read.

Communication

11. Clinicians to communicate directly with the person with a learning disability about their health and care, and not their carer or support worker.
12. Clinicians to avoid sharing information, such as test results, with people with learning disabilities by telephone. This can cause unnecessary concern and anxiety.
13. Clinicians and reception staff to treat people with learning disabilities with kindness and respect. Reminders and refresher training on engaging with people with learning disabilities should also be considered.
14. Clinicians and reception staff to never question whether a patient has a learning disability, and must meet their needs accordingly.
15. GP practices to deliver Customer Care training for reception staff to improve their customer service and communication skills.

Support with Living a Healthy Lifestyle

16. Clinicians to provide practical information about healthy eating, weight management and exercise, including meal and exercise plans.
 - Any information is to be provided in Easy Read and/or a format which is accessible to the patient.
 - Any support is to be tailored to their individual needs.
17. Clinicians to have regular discussions about mental health, sexual health, drugs, alcohol intake and smoking, and to ensure any support provided is personalised to their needs.
18. Clinicians to talk to people with learning disabilities about cancer screenings, ensure any relevant tests are carried out, and provide information on how to check their body for any signs of cancer.

Annual Health Checks

19. Clinicians to allow between 30 minutes to one hour for an Annual Health Check.
20. Clinicians to provide a full examination of the individual's physical and mental health. This is not to be carried out by telephone appointment only.
21. GP practices to ensure that people with learning disabilities are offered an Annual Health Check and reminded as to when their Annual Health Check is due.