# Digital Vision for Personalised Care
# People with learning disabilities



Report by Brighton and Hove Speak Out

March – May 2020

## Speak Out

Speak Out is an independent advocacy organisation working with adults with learning disabilities living in the Brighton and Hove area. We work with people in several ways including 1:1 issue advocacy, Self-advocacy groups and drop in services around the city. Our self-advocacy groups represent key demographics, such as young people, older people and an LGBTQ group. We also have a regular presence in day services, sheltered housing, residential homes and supported living throughout Brighton and Hove. We continue to explore new ways of engaging hard to reach and marginalised individuals whose views often go unexpressed.

## Methodology:

People with learning disabilities tell us that face to face communication works best for them. We conducted one to one interviews to ensure people felt able to express themselves fully and freely. We held a focus group comprising of people with a broad range of support needs giving people the opportunity to explore issues and come up with creative solutions. Speak Out are also able to use intelligence gathered from detailed consultations commissioned by the CCG and Local Authority on the following subjects:

- Support needed to manage an online universal credit claim
- How online GP services might work for people with learning disabilities
- Managing multiple long term health conditions
- Social prescribing for adults with learning disabilities

We are also informed by issues that arise at our drop ins and through one to one advocacy case work. In this instance we have been able to make observations through moving to online self-advocacy group meetings.

## Demographic

We spoke to 24 people with different support needs, living situations and levels of independence. All participants were residents of Brighton and Hove and between the ages of 16 and 85.

**Accomodation**
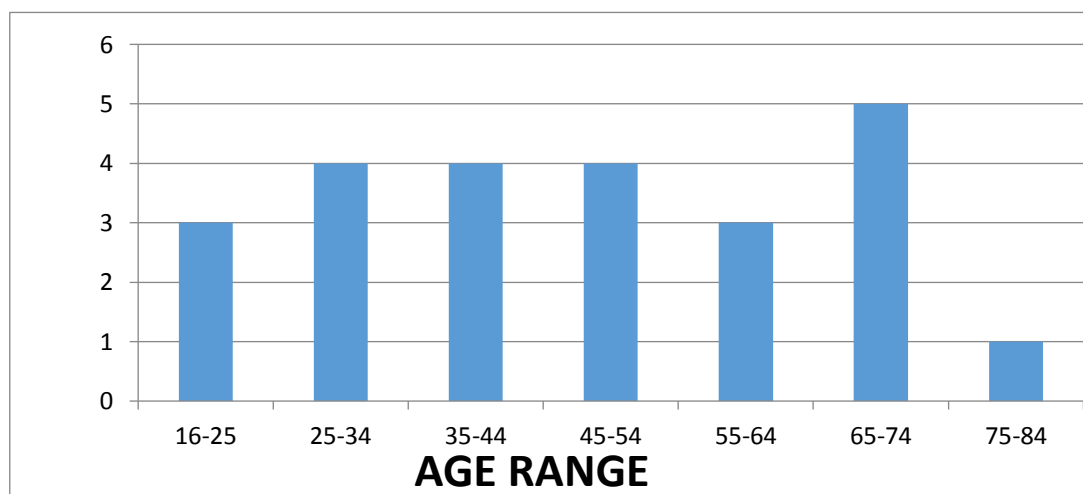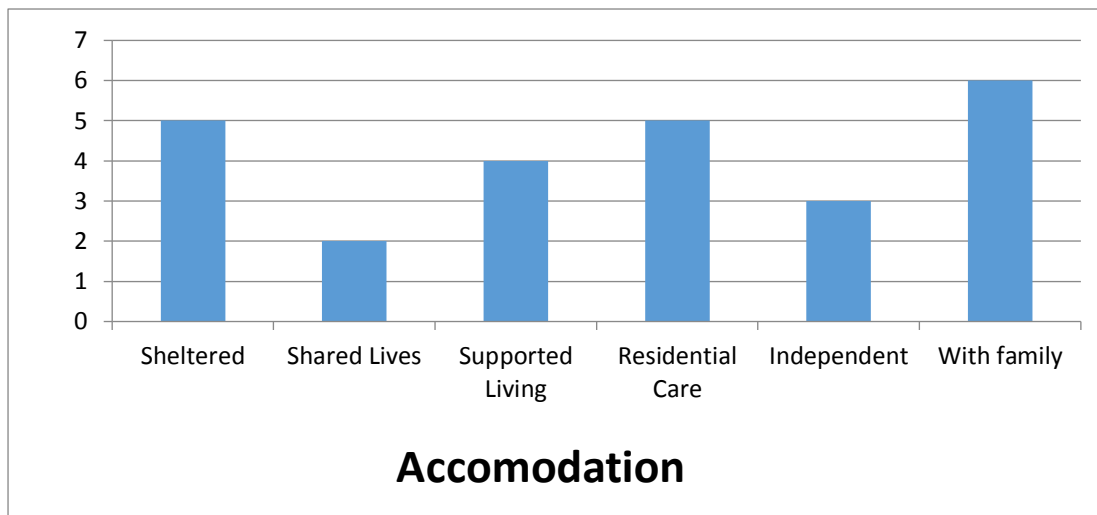
## Consultation subject

Personalised care aims to give choice and control over the delivery and planning of an individual's healthcare according to their own priorities. As part of the NHS long term plan it contributes towards the goals of prevention and self-management of health issues. The NHS seeks to 'Empower people to participate in their health and care using digital services.' to achieve these aims

The last few years have seen many GP services moving online: including managing appointments, ordering prescriptions, viewing medication and in some cases skype appointments with a doctor. Symptom checkers and information about medical conditions are also on offer. The services also free up phone lines and face to face appointments for those most in need and are more time efficient for both staff and those accessing digital services,

However the use of digital platforms is known to exclude certain vulnerable groups. Digital exclusion is most common among the elderly, those on a low income and people with learning disabilities.

These barriers magnify the pre-existing inequalities in health and life expectancy faced by people with learning disabilities.

People with learning disabilities experience significant, well documented health inequalities. These lead to a life expectancy that is well below that of the general population. Men with learning disabilities die on average 14 years earlier and women 18 years earlier. People with learning disabilities are 58 times more likely to die before they are 50.

Incidence of the five risk factors identified by the NHS long term plan are more prevalent in people with learning disabilities.

1. Hypertension and breathing problems
2. Obesity and high cholesterol
3. Hyperglycaemia

4. Frailty and fall
5. Anxiety and depression
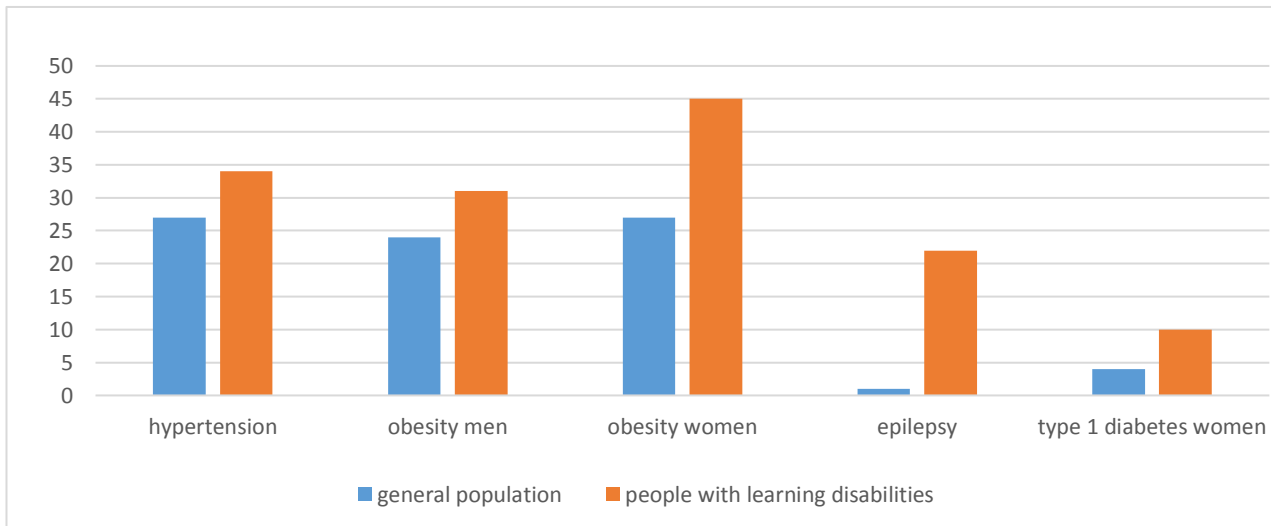


## This Report

This report explores how digital services can adapt to face the challenge of accessibility whilst understanding that for some the 'digital first' option will lead to further marginalisation and the risk of crisis situations.
If delivered with the access needs of people with learning disabilities taken into account the Long Term Plan stands to significantly benefit the health outcomes of this group. Digitalised personalised care addresses many of the issues that people with learning disabilities say are important to them in terms of health care.

- Professionals often don't have the right information so people with learning disabilities need to relay complicated medical facts multiple times.
- They experience multiple long term health conditions and are not dealt with as a 'whole person'.
- They would like to be referred into lifestyle improvement services
- They would like their learning disability to be flagged
- They would like to receive health information in accessible formats
- They would like their records to be kept in one centralised place
- They want to have their statutory rights to an Annual Health Check, Health Action Plan and longer appointments recognised.
- They want choice and ownership over their health care

However, people with learning disabilities tell us there are numerous reasons the online world is closed to them:

- It is too expensive. People say they can't afford data and technology on a low income
- Lack of cognitive ability
- Lack of literacy skills. Browsing and accessing content rely on being able to read and write

- Inability to assess information
- Websites are inaccessible. Too much information, jargon and a lack of pictures.
- No support
- No access to computer
- Lack of skills
- Lack of education/training
- Fear of being hacked or scammed

## Current context

At the time of writing there are a number of restrictions in place owing to the coronavirus outbreak. This has resulted in much of our work moving into online platforms and being carried out over the phone. This has given us a unique insight into the barriers that people with learning disabilities face in a society where services are becoming digital by default. We have also been able to observe the positive aspects of digital connection for our cohort and identify what systems are most accessible to them.

## Who manages your healthcare appointments etc?

Use of digital personalised care will be undertaken by the person or service that currently manages appointments, medication etc for an individual. This task is daunting and complex meaning that most people with learning disabilities rely on someone else to do it for them.

We asked people who is in charge of managing their appointments with GPs and other healthcare professionals

- Sheltered Housing
  People in sheltered housing say that their support worker makes their appointments and accompanies them. They are also able to go to the onsite office to speak to staff if necessary.
  Everyone we spoke to in sheltered housing said that a support worker is in charge of making their appointments and dealing with health care.
  Those with close family also get support from family members.

- Living with family
  People say that their family members manage their appointments and resulting medication, referrals etc.
  In a few cases the family members themselves may experience difficulties accessing care due to mild learning disabilities, mental health problems and other conditions.

- Shared Lives
  People told us Shared Lives carers take responsibility for managing their healthcare.

- Residential Care
Medical documents, appointments and issues are overseen and managed by the home.

- Supported Living
Supported living housing offers an extremely wide range of levels of support and in house care. Some people require round the clock one to one support in their own flat. This means that medical issues are dealt with and appointments managed and attended by staff.
Others may live more independently and only have a support worker at designated times to help with arranging appointments shopping etc. The support worker might not be on hand to help when needed.

Support from carers, family and social care workers is essential to ensure that people can access the healthcare they need. However there can be problems associated with having healthcare managed by someone else.

- Family members may lack the skills to deal with more complex processes and referrals. Family members may also have a mild learning disability.

- A change in someone's health may not be reflected in the support hours they receive. The result is that people may not be able to attend appointments or get the information they need.

- The quality of the support people get to navigate the health care system is dependent on the individual supporting them. Not everyone receives the same standard of support around their health needs.

- Health crises may happen on a day or time when a person does not receive support.

- In the majority of cases digitalised personalised care would be managed by those who support people with learning disabilities
- The success of this will be dependent on the time, skills and willingness of staff, social care, families and carers
- Focus needs to be on people with mild learning disabilities who have very little support as digital exclusion affects them most

# Who do you trust with your information?

Digitalised personalised care involves an amount of highly sensitive and sometimes financial information. The majority of people with learning disabilities will need someone else to manage their account. Most people said they would always ask the same person for support. They would entrust their claim to someone they have known for some time and had gained their confidence. The most likely to be trusted are regular support workers and family members.

*'We would need to have known them a long time as they may steal your identity or other details.'*

Others trust people in positions of authority such as office staff or scheme managers whether they have a relationship with them or not. These professionals may be able to deal with a one off query but would not have the time to manage an ongoing account.

*'I would get a scheme manager to help. There's always someone around.'*

Another issue raised by people who rely on support workers is that different support workers have varying levels of experience and skill using online tools.

*'One carer is good at going on the internet, but it stresses them out. One carer is not good. One of my carers is rubbish.'*

*'I don't get consistency if the carer is away.'*

*'The staff here come and go.'*

Three people said they would ask whoever was available. This leaves people vulnerable.

Three people with little or no support said there was no individual they could ask to help.

*'I haven't got anyone that could help.'*

Two people with high levels of independence expressed great anxiety about the security of using online systems. One person said she felt anxious about having any online accounts at all, feeling it would leave her vulnerable to crime or identity theft even if it was managed by someone trustworthy with the correct skills.

- People may need to have one named person to support them with their account
- Those new to someone's account may not have the background knowledge of that person's circumstances.
- The person they approach may not be trustworthy; there is scope for financial abuse.
- People may not have their choices explained to them properly
- People may not have their choices respected

## Do you use the internet independently?

In planning digital personalised care for people with learning disabilities it is important to identify those who may be using the system with very little or no support.

- Those living in residential care do not access the internet independently. They are supported to access emails. Some homes do not have any digital provision for residents

- People living in supported living sometimes have their own email address. Staff manage and oversee email accounts, sending and receiving email.

- Of the people we spoke to in sheltered housing none have an email address. One person has a tablet but only uses it to play games.

- Some of those living independently with little or no support use their smartphones for social media and messaging platforms. They say that they cannot manage accounts online as they are difficult to understand and navigate

- People living at home with family rely on family members to support them with the internet. Those who use the internet access social media, messaging and streaming sites.

- None of the people interviewed in shared lives placements use accounts. Some use social media and messaging

Interviews and focus groups showed that the majority people do not use digital services. People over 40 told us if they have an email address they need support to use it. None manage online accounts or use passwords.

All of the 7 people under the age of 25 that we spoke to told us that they have access to the internet and have an email address. 4 people use passwords and 2 people have online banking. However all of them said they need support to fill in online forms and set up and manage accounts.

Some people may have access to a computer but no support to use it.

*'I've got one upstairs, but I can't get on with it. I need someone to go on it with me. I want to go on the internet to look things up.'*



- Those who use digital platforms are people with the highest levels of independence.
- The majority of them are aged under 40
- Their main use is through smart phones
- They say that they still require support with administrative tasks such as passwords
- They do not manage finance, health or social care digitally.

## How digital works successfully for people with learning disabilities

Despite the obvious barriers to digital services there are ways that systems and education can be developed to benefit some people with learning disabilities. This could contribute to narrowing the gap as more and more services go online in the future. Young people use a variety of online platforms for social networking and messaging. They also told us that they use the internet to shop and find information and entertainment. We also learned that people from all age groups adapt technology to meet their needs.

S, (35-44) supported living: *'I've got an iPhone. If my mum texts me I get Siri to read it. If I get a letter through the door and no one can help me read it I take a picture and send the photo on WhatsApp. I use WhatsApp and Facetime.'*

C, (25-34) independent: *'I can't read. I use Siri to look things up and get information. I want to invent a website for people with learning disabilities. One that is disability friendly.'*

S, (25-34): '*One thing that is good for me is that I can make writing bigger on my phone. I can read but a lot of the time the writing is too small. If it's on my phone I can make it bigger and put it in an easy font.*'

J, (25-34) lives with family: '*I can't read. But I love YouTube. I watch the videos all the time. Some of them about autism. I learn lots of stuff and you can learn how to make things.*'

S, (25-34) independent: '*I love my Xbox, I can connect with my cousins. I don't have to sign in every time. It just stays signed in. That's important otherwise it is too hard.*'

K, (25-34), independent: '*Being on Zoom has been brilliant in lockdown. All I have to do is click on a link. If I get stuck I ring the person up and they help.*'

These people had all been creative in their use of technology and open to its possibilities. However they still identified themselves as not being able to navigate services, online forms or written information.
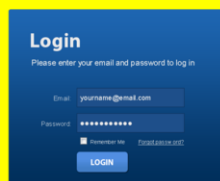


- Filmed content is a very effective way of delivering information.
- People use the following:
  YouTube, Snapchat, WhatsApp, Facebook, Vimeo, Instagram
- People do not like:
  Online forms, written information, passwords, user ids
- People find 'signing in' difficult

## Adjustments to websites for people with learning disabilities

Significant work is required to make digital services accessible to people with learning disabilities. NHS England states that online services should be as simple as possible as standard. In order to ensure continued use of systems they should be well tested, of high quality and not subject to 'glitches'.

People with learning disabilities have consistently told us that face to face contact is their preferred option. However they have a very clear view of how websites can be made more accessible

- Film: deliver information by film not text
- Images: plenty of photographs to support text
- Large well defined buttons

- Audio description on buttons
- Contrast button to change background or text colour
- Magnifier for text

A good example is the EasyHealth website https://www.easyhealth.org.uk/ People with learning disabilities say that it is uncluttered, easy to understand and has a good mix of filmed content.

These measures delivered as standard provide a better service to other vulnerable groups at risk of being excluded. Including people with specific learning difficulties like dyslexia, people with visual impairments, those with English as a second language and the elderly.

Carers, support workers and families are also able to include those they support if a website is more accessible, specifically in the case of those seeking information about certain conditions and treatments. This contributes to a feeling of ownership that makes people more engaged with their health and wellbeing.

- Websites must be accessible:

  This means no jargon, Lots of pictures, larger font size, not too many words, not too cluttered

- People also like films and audio description to help them understand information

## Who could benefit?

The barriers will be insurmountable for some who will always need a face to face service. However there are some groups of people with learning disabilities who can benefit from online systems with the right adjustments and support.

As mentioned previously all the young people we spoke to say they use the internet. Those who live at home are preparing themselves for a more independent life in the future. All of them have the goal of moving out of the family home to live with varying degrees of support in the community. They would all like to be more in control of their healthcare but say that they struggle to manage it on their own.

'*My mum helps me ring up. If they are not helpful I get her to talk to them.*'

*'It's hard to get an appointment; you have to keep repeating yourself.'*

Without reasonable adjustments to online systems they could find themselves struggling to negotiate healthcare without the support of their family.

It is important to capitalise on the existing skills and confidence they have and consider their needs when developing online services, training and education.

Tools that this group say they already use could prove a good basis for planning a more accessible system. There is a willingness to use social media, messaging and streaming which is transferable to other online systems.

It has also been reported (Health Information Online for People with a Learning Disability, Change 2016) that degree of literacy was not found to be correlated with use of computers. This means those with lower literacy skills could still benefit from online services with the right support and training.

There is evidence of a need for these digital skills to be part of a young person's EHCP where appropriate and where the individual has capacity. This needs to be considered as a major factor in the move towards greater independence in the future.

Where appropriate training in education could encourage a generation of 'digital natives' who are comfortable using technologies for a variety of purposes in.

Further consultation is required around how best to support people's independent use of online systems. People with learning disabilities are very clear about how they learn effectively.

'*For me, if they gave it to me on paper, pictures of what was on the screen and where I have to click …..I could go away on my own and have a look. I am a visual learner and I need to be by myself to concentrate.'*

*'If someone was on the phone and talked me through it. I could ask them questions and they could tell me what I need to do.'*

- People say they want to learn new digital skills

- They want to learn in a way that works for them

- They want to be in charge of their choices

## Case Study: Online Self-advocacy group during Corona Virus Lockdown

The Link Group are a self-advocacy group who meet every fortnight to discuss local service provision and access. They work in partnership with the council to improve services. During the social distancing restrictions the group has been having online zoom meetings. Their individual situations and support needs provide an insight into some of the issues facing people with learning disabilities.

D (55-64). She lives in a residential care home.. D has been unable to join us for zoom meetings. There is no longer a computer in the home as residents didn't use it. She has no mobile phone or any other device.

K (45-54). She lives independently. Her literacy skills are excellent and she is always keen to find more information about politics and other areas that interest her. She has not been able to join us for zoom meetings as she does not own any device. She has a high level of anxiety around the internet and does not want to use a smartphone. She finds phone calls much easier.

L (35-44), she lives with shared lives carer's. L enjoys high levels of independence. She experiences high anxiety and will not use a smart phone. She uses her ipad to watch nature films. She has been able to join Zoom meetings in the following way: The link for the zoom is sent to her shared lives carer, who then sends the link to L's ipad, the carer then accesses the link on the ipad and gives ipad to L.

S (25-34). She lives independently and receives a support package to help her with shopping and organising. During this time she has moved back in with her family. She does not read but navigates Youtube and other streaming sites on her phone and laptop. A link is texted to S and her mother supports her to access it. If there are difficulties she rings the member of staff hosting the meeting who talks her through the process. If she was at home without the support of her mother this could prove more problematic.

I (65-74). He lives in a residential care home. He is highly literate. He is supported to use the computer at home. The Zoom link is sent both to home manager and I by email. Staff then support him to access the link.

C (25-34). She lives at home with her family. She receives no support at all. She receives the link by text and has no problem accessing meetings. She is also using Facebook group chats and pages to stay connected at this time.

N is (35-44), he lives in supported living. He has round the clock one to one support. He has a wide range of interests that are facilitated by his support staff. A link is sent to his email address and staff access meetings.

- Everybody has different support needs
- Different things work for different people
- It's important that services are flexible
- People need to use services in a way that suits them

# What people told us

- People with learning disabilities prefer face to face contact
- Most people with learning disabilities have their health care managed by staff, carers, support workers or family
- Those who are independent are more likely to manage their own health care
- People find passwords and form filling very hard, if not impossible
- Those over forty struggle with the digital divide and are unlikely to own a device
- The majority of young people access the online world through smartphones
- Most people use social media and streaming but say they are unable to use most other websites
- People say they are not getting health information in a way they can understand
- Text based information does not work for the majority of people with learning disabilities
- People with learning disabilities are at an economic disadvantage making it hard to be online.

# Recommendations

- For people with learning disabilities services must never be digital by default. This should only be an option where appropriate.
- People with learning disabilities should be on their Surgery's Learning Disability Register. This register flags up people's needs and statutory entitlements to reasonable adjustments. People on this register should only receive a digital service as an 'Opt In'
- People on the learning disability register who wish to opt in must be offered ongoing support with the service. ( Tech support/trouble shooting helpline)
- Ongoing monitoring must be carried out to identify unforeseen problem areas.( Problems may only be noticed when something has gone wrong, which may have serious implications for a vulnerable patient)
- The service should adhere to easy read guidelines around images, fonts, adjustable font size, background contrast and colours.
  - Where possible health information ( eg about specific health complaints) should be delivered by video.
  - Where possible audio description should be used
  - Clear pictures and symbols need to be used
  - The screen must be uncluttered
  - Text should be kept to a minimum
- Work developing these tools needs to be done in accordance with the Accessible Information Standard
- User testing to be carried out with young people who are moving towards a more independent life.
- User testing to be carried out with college pupils with learning disability.

Brighton and Hove Speak Out supported a group of people with learning disabilities to present their views on the website directory of local services. If you would like to see their feedback please email emmalopez@bhspeakout.org.uk