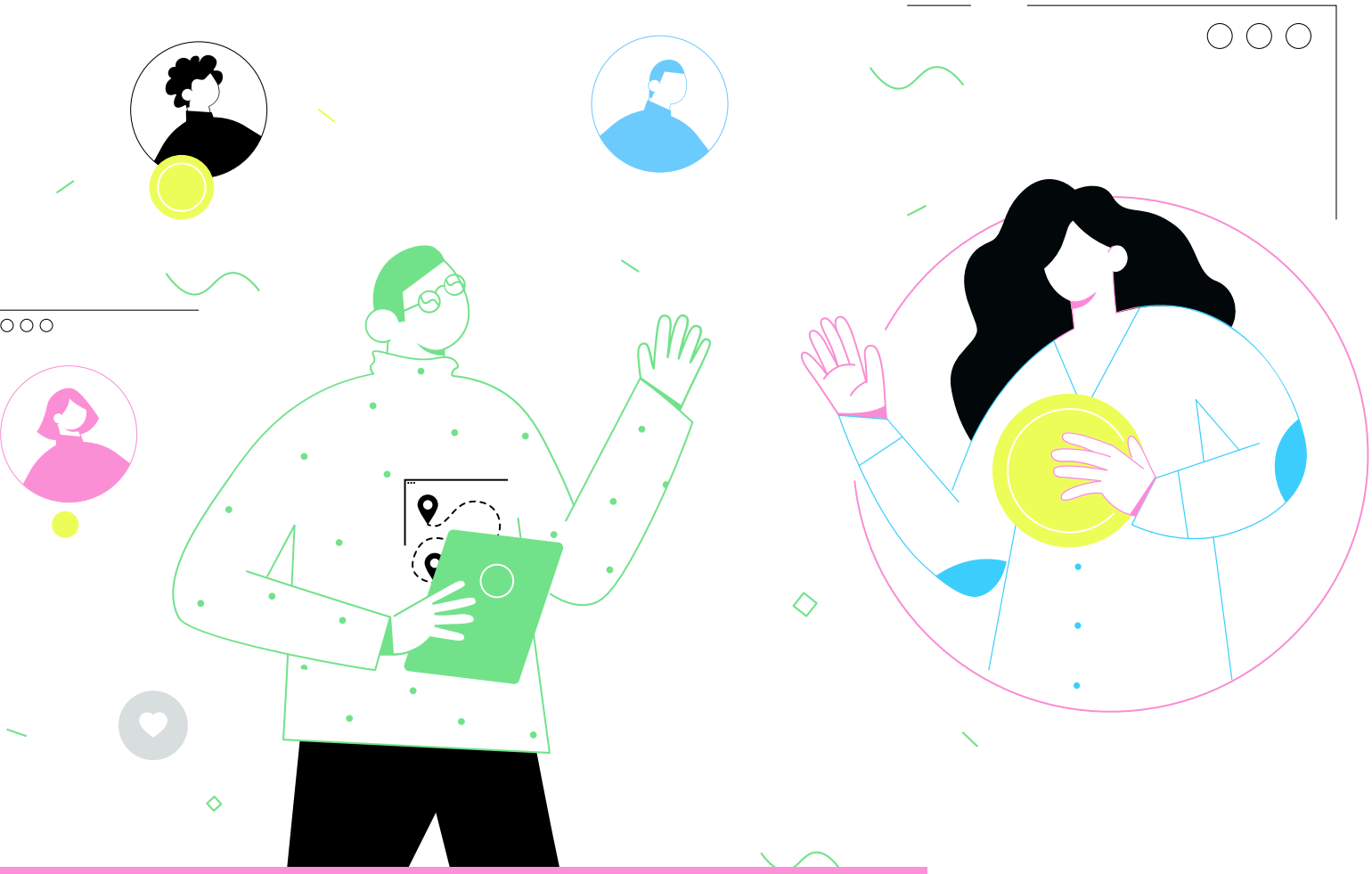
REASON DIGITAL



# Mencap Discovery Research Report

# Project introduction

Mencap presented us with a challenge. The overall goal was to design a more accessible website, while being able to formalise and share our learnings as we go, to allow other organisations to improve the accessibility of their websites. This is strongly in line with the organisational vision to make the UK the best place for people with a learning disability to live happy and healthy lives.

This challenge can be segmented into three core focuses, which formed the objectives for this project:

**Develop a clear understanding of the users of Mencap's website – their needs, challenges and lived experience**

**Create accessibility guidelines and/or standards for people with a learning disability**

**Redesign the Mencap website, factoring in the outcomes from the two previous objectives**

This report summarises the findings of the Discovery phase of the project. The work in this phase of the project has primarily focused on the first objective listed above, with some considerations for the second objective.

I listened to
I texted my
On whatsapp.
eastenders
time capsle
DaD and my
our internet diary
e the logos to show what you've used today
YouTube
Spotify
FLIX
BBC
PLAYER
prime video

# Research objectives

Ensuring that our understanding of Mencap's audience is both broad enough to see the website's role in their wider digital experience accurately, and in-depth enough to respond to their challenges and needs with confidence, led to us selecting a range of complementary research methods. With all the research we conducted, we led with the same research questions:

- ☑ To understand the lived experience of different people with a learning disability and their support networks
- ☑ To represent and design for people with a learning disability accurately and responsibly
- ☑ To develop a strong understanding of Mencap's organisational ethos, challenges and priorities
- ☑ To understand how Mencap's frontline services are delivered.

# Research plan

To answer these research questions with both perspective and depth, we designed a research plan:

- ☑ Immersion sessions with the fundraising team and Exec team
- ☑ A cultural probe to understand how people with a learning disability (PWLD) access digital
- ☑ A survey into how PWLD and their supporters access digital
- ☑ Interviews with professionals who work with PWLD
- ☑ Interviews with some of the Mencap team who have a learning disability
- ☑ A review of the current website's UX and search visibility

# Method

We worked closely with Mencap to establish an approach that would align with the objectives of the project, the needs of the participants, and the ethos of the organisation.

Our goal was to **design an approach with inclusivity underlining everything**, respecting the contributions, needs and preferences of participants. We wanted to put qualitative insight at the heart of our approach, using the stories and experiences of individuals to set our design direction and inform our accessibility standards.

### Cultural Probe

8 participants
over 4 weeks of study

**Insights into lived experience of PWLD**

### User Surveys by Mencap

142 participants
41 questions answered

**Valuable data on digital experience of PWLD**

### Depth Interviews

Expert participants including healthcare professionals.

**Understanding of frontline services & who they serve**

### Workshops & Immersion

9 participants
283 Post-Its

**Defining Mencap's ethos, challenges & priorities**

### Call Recordings

10 helpline calls
105 minutes of audio

**Immersion into frontline service delivery**

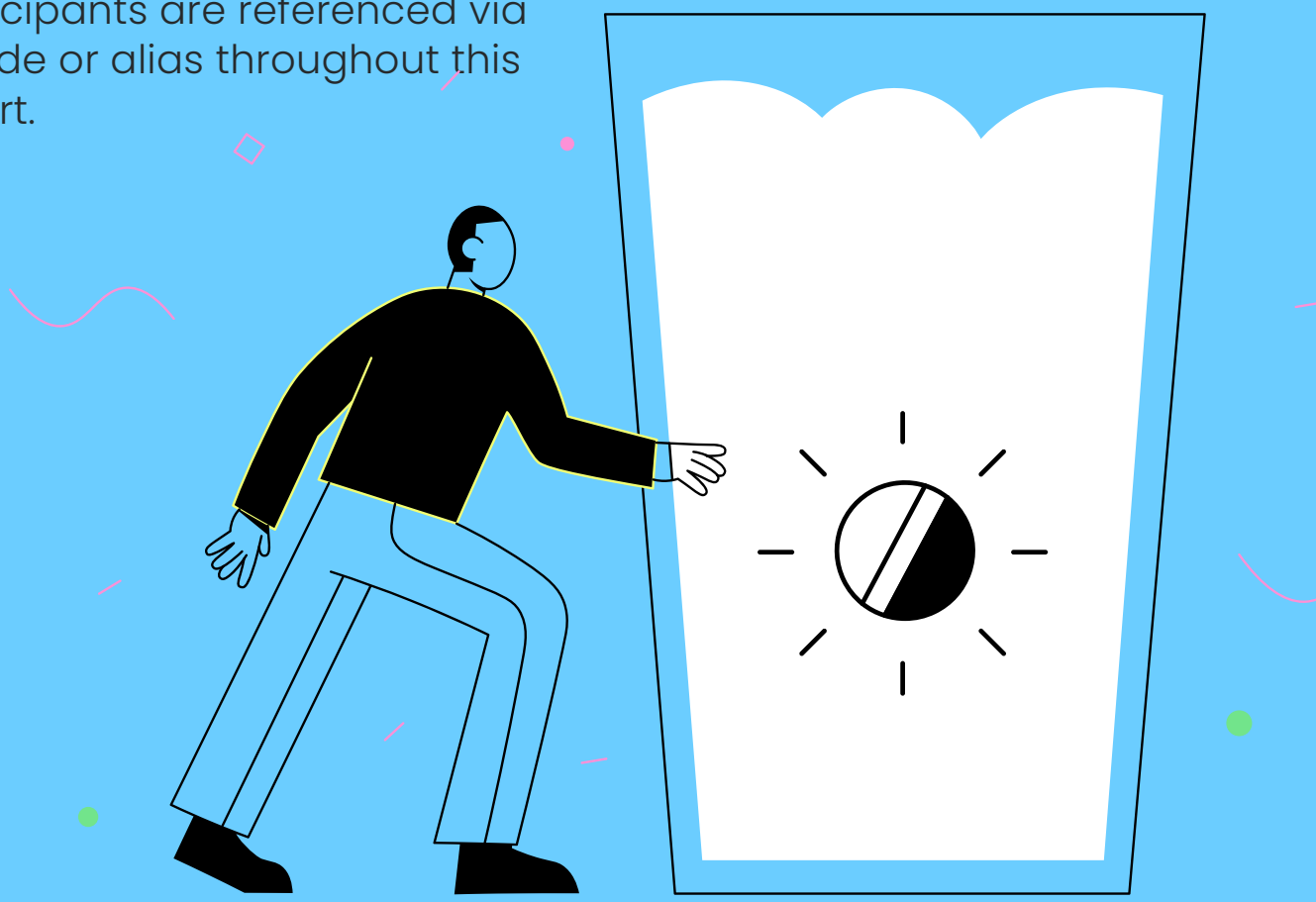
### Website & SEO Review

24 hours of analysis
Consolidated report

**Benchmarking current digital performance**

# Ethics and consent

**We were particularly careful about our data protection and consent processes.** Participants in the research needed to understand that they could withdraw consent at any point, and that we would also withdraw and delete the information they had provided. We anonymised our participants, deleting personal information such as addresses as soon as we had no need for it. Transcriptions and other recordings have been anonymised at source, and participants are referenced via a code or alias throughout this report.



# Immersion sessions & workshops

We carried out a number of workshops with staff members to understand the organisation, individual concerns, challenges and aspirations.

We have also produced work-in-progress reports on the individual bits of research as we've completed them.

We could also make use of research and insight previously carried out by Mencap, most recently a survey conducted via the website.

# Website analysis

The website analysis included a combination of different research pieces:

An Expert UX review of the website, reviewing the current design and navigation in line with UX principles of accessibility

Keyword analysis, reviewing data from organic search, paid search and Ads Grants to understand how people access the Mencap website, where they land, and what they do next

Entry point point analysis, identifying common landing experiences on the website

Conversion analysis, reviewing behaviours around key actions including donations and helpline calls

The findings of this analysis was presented to Mencap project team on 27 February.

The presentation can be found here:
**Mencap RD SEO and UX Review of Current Website Jan 23.pdf**

# Cultural Probe

**A cultural probe is an umbrella term to describe a method which combines social research and co-design.** It might take the form of a diary for participants to fill in, a disposable camera to fill with pictures, or any number of other activities. They are characterised by giving a participant a task to complete independently without a researcher present.

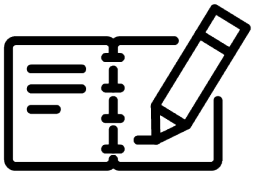
Because every learning disability is different, **our cultural probe needed to be accessible to people with a wide range of conditions and challenges.** We created a probe which could be customised to the individual's preferences and needs: some opted to participate on paper, where we posted out the activities with pre-paid envelopes to return to us. Others completed the activities on WhatsApp or on voice calls. We codesigned this approach with Mencap staff, including staff with a learning disability, and piloted the activities before sending them out to our recruited participants.

We aimed to reach 10 households (some activities were carried out by a participant with a learning disability, others by friends and family). Given the complexity of the research, we expected a number of drop outs – but even those few participants who didn't complete **every activity gave us valuable insight from the contributions** they did make.

# Our cultural probe process

## Briefing call

To confirm consent and how they would like to participate in activities



## Probe activities

Completed through activity book, video, messages or email.

## Debrief

Interview with participant, probing on their submissions.

We gave participants small, 'one sheet' activities to complete over the course of about ten days. **We asked them to circle what digital experiences they had used, who their circle of support was, and about their interests.** We used the 'Easy Read' format to inform our design of the activities, using large format text accompanied by photo icons.

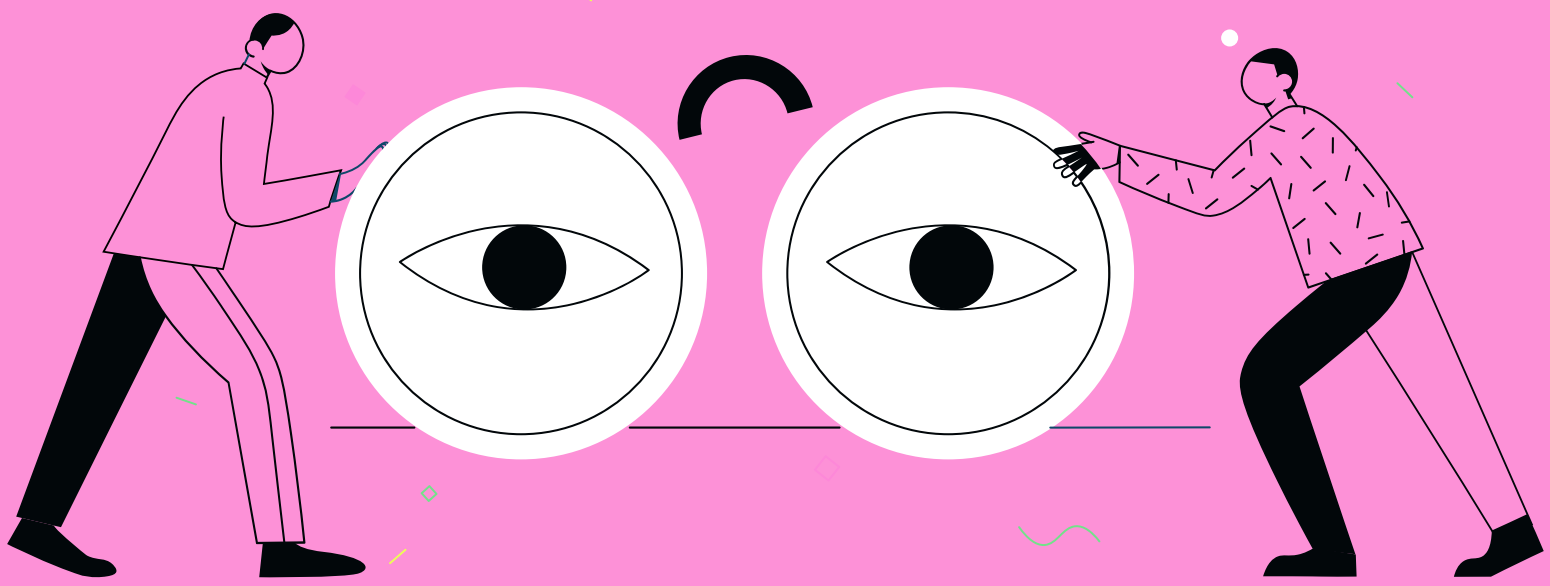
# Analysis

We used 'Lines of Enquiry' to organise our findings by the objectives set out in the introduction. We have worked through the transcripts of our interviews to highlight and organise pieces of evidence. From this analysis, we have pulled out the themes you can see in this report. From here, we are able to make recommendations, give direction for design, and identify opportunities for further research or digital strategy.

# Limitations

Most of our methods have been qualitative. By this we mean we have worked with very small numbers of participants to gather rich data: to confirm that these constitute part of a wider trend, the work would need to be supported by quantitative research, in the form of larger scale surveys, site analytics or studies.

We suggest that because of Mencap's national standing, we could partner with academic institutions to continue to build on our understanding of the lived experience of people with a learning disability – the standards and designs that we develop should be a living part of a continuum of research into the area.



# Executive Summary

Our research had painted a picture of a diverse range of needs.

There is **no ladder or scale that can be used to define boundaries between specific level or types of need**. Needs and preferences are so unique to the individual, that creating personas to embody these behaviours isn't likely to be a useful exercise.

Levels of **digital literacy vary across different digital activities** – some people may be happy looking at recipes, others sending emails or signing petitions. Some can do this alone, others enjoy the activities but require support.

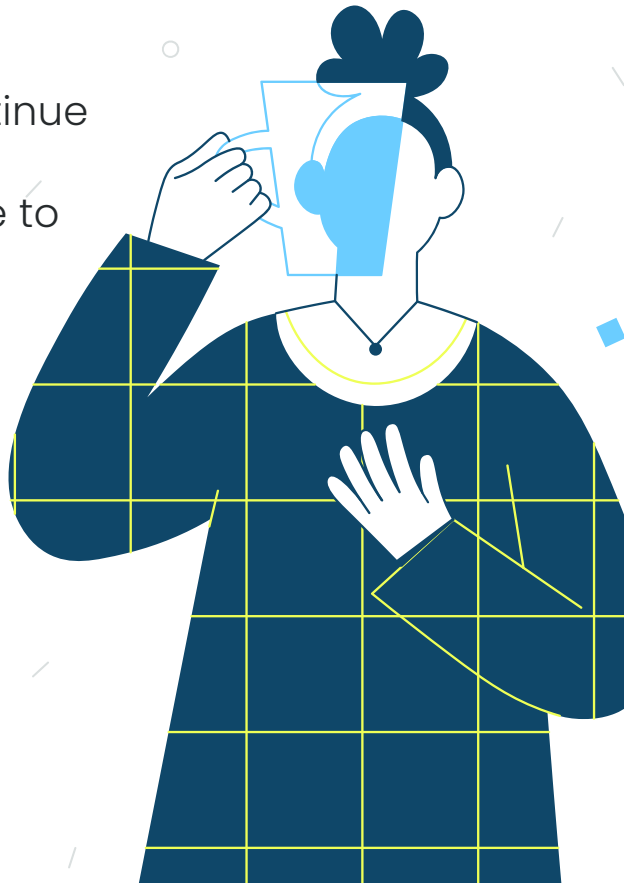
**Accessibility needs are compounded by other complexities, such as anxiety around "getting it wrong"**. Instilling confidence will be as important as responding to accessibility needs.

**Supporters navigate a complex landscape when seeking support and advice**, often not knowing where to turn or what to look for. Clarity and simplicity of language is likely to aid both PWLD and their supporters.

Currently, **not many PWLD or their supporters report using the Mencap website**. Exploring the role and purpose of the website, as well as how content is positioned and presented will be as important as a redesign in increasing usage.

This presentation and the accompanying written report detail the amount of work that has gone into these findings. **Even with this depth of research, we won't have tackled every aspect of the challenge** – this is just our contribution, and can sit alongside WCAG's guidelines.

**We see this as a start, not an end.** Moving forward, we recommend that Mencap continue to explore the digital experiences of their beneficiaries, as these are likely to continue to evolve over time.



# People with learning disability and their experiences with digital

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At the start of our research, we expected to find that **people's experiences with digital were highly varied.** The research showed this to be true, although we uncovered common themes that impacted many digital experiences, to lesser or greater extents. By the nature of our research, these findings are qualitative, and we are not able to quantify exactly what proportions of people are affected by each theme, or determine to what specific level they are affected.

We did not ask participants what their medical diagnoses were, whether regarding their learning disability or any other conditions. **We followed Mencap's social model of learning disability**, seeking to understand the needs experienced by a person to navigate the world, rather than by looking at a diagnosis.

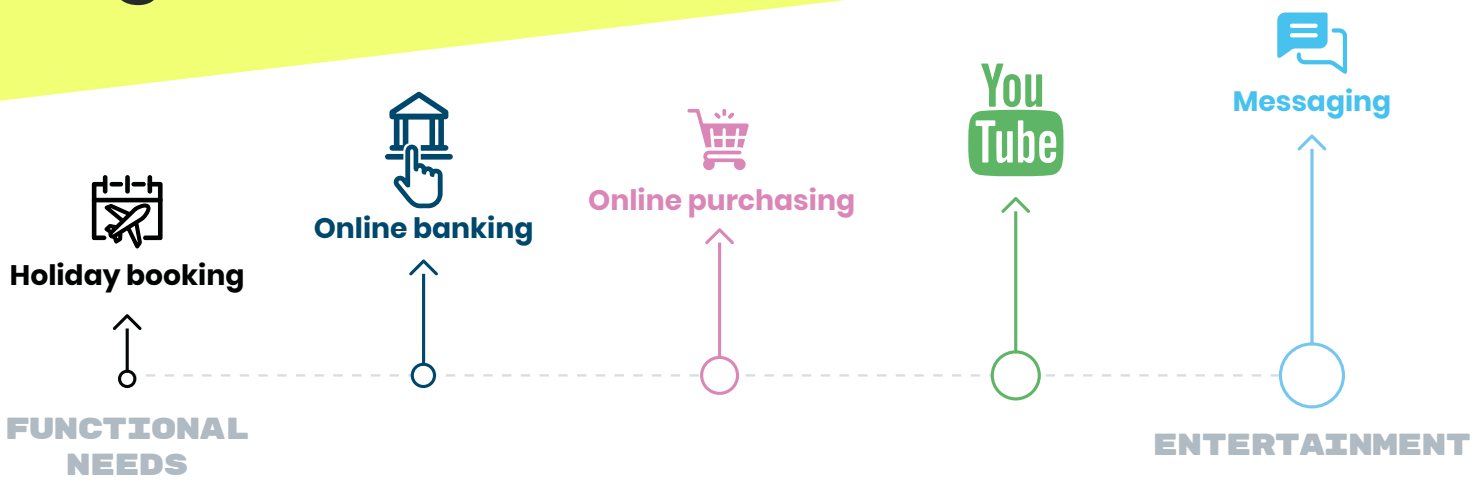
# Exploring variances in needs and experiences for PWLD

The participants in our research lead rich, varied lives. People talked about pets, boyfriends, calling grandparents, going to work or college, writing, dancing and playing music and games consoles**. It would be incredibly reductive to wrap all of these lives into one common experience.**

However, within this huge variation in lifestyles, **we discovered common needs and challenges.** Anxiety, digital literacy, and complexity of a task all impacted whether a person was likely to use digital in that area of their lives.

make
your
dreams
happen

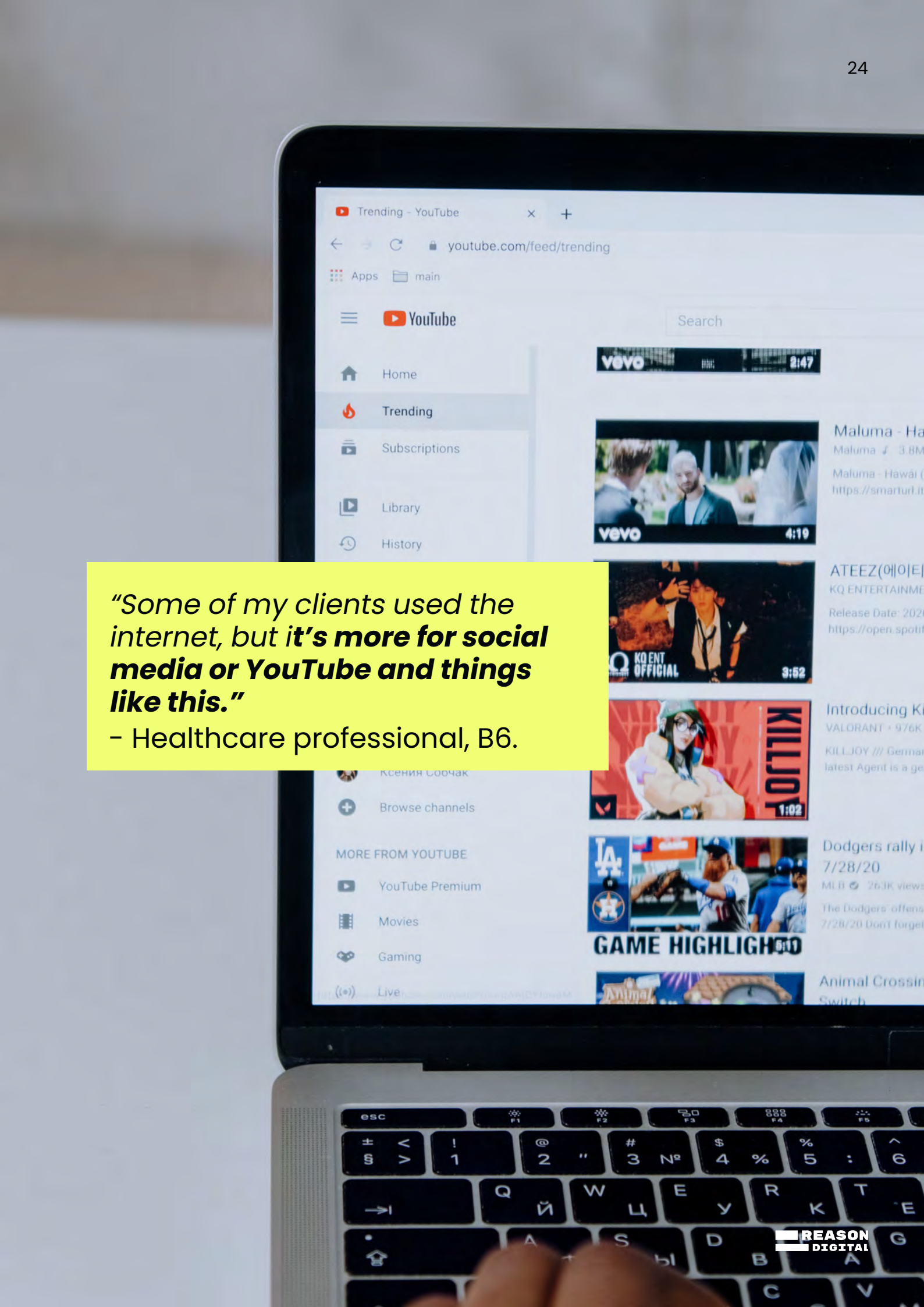
# When do people with learning disability use digital?




The research found that digital is **generally used for entertainment purposes over functional purposes**. Many participants spoke about listening to music and chatting with friends online. Netflix and YouTube were often mentioned, alongside searching for football results and planning fantasy football teams, searching for recipes, or using WhatsApp and games consoles.

We didn't hear mention of activities like online banking, booking a holiday or event tickets, finding accommodation, or paying bills. It's not clear whether these activities are less common due to accessibility barriers of digital, or whether these activities in themselves are too complex for some PWLD to manage.

However, **this isn't to say that no participants reported functional or financial use of digital, just that it is less common.** Some reported asking for support when carrying out these activities, such as one participant who would shop online and add to basket, but ask a parent to complete the transaction.




*"Some of my clients used the internet, but i**t's more for social media or YouTube and things like this."***

- Healthcare professional, B6.

REASON DIGITAL

*"So I look for tips on different weeks of fantasy football for players I should bring in. And because there's a lot of players when you type in a search search engine to do about fantasy football and I try to find the right page to go to do that... **I don't need help on them because I try to fight for my place to go up the table and keep my secrets..."***
- Mahmoud, Post-probe interview, A7.

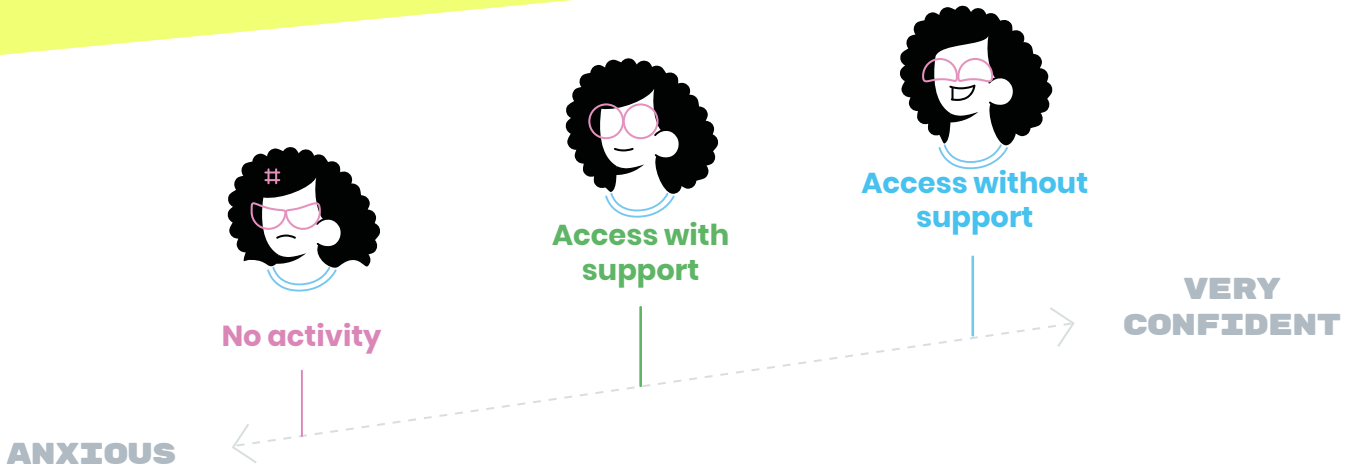
# Outstanding questions

1 How might we **identify the most accessible elements of popular platforms?**

2 Are there specific **elements that make these platforms more popular** – or are they just the market leaders in the entertainment formats they deliver?

3 How might we **replicate or be inspired by familiar design elements** in our design?

# How confident are PWLD using digital?




Our different modes of research painted two distinct pictures in terms of levels of confidence.

The survey, which PWLD responded to directly, found that high numbers of PWLD are completely comfortable in accessing the internet alone, without any need for support.

On the other hand, speaking to supporters and professionals, we were informed about high levels of need, of PWLD not being confident (or not able) to go online alone.

This can be explained by how participants were selected – PWLD who are able to respond to an online survey have higher levels of digital literacy and self-report high levels of confidence in going online alone. On the other hand, PWLD who are in receipt of more professional support are less likely to be confident in managing day to day tasks alone.

Within our sample, we spoke to some PWLD who work, and lead more independent lives. These people had much higher levels of digital literacy, but still reported some levels of anxiety in going online. Barriers included unfamiliar UI, and security measures such as log ins or two-factor authentication.

The role of an intermediary in mitigating anxiety is inconsistent between people we spoke to. Some PWLD will seek support if a site becomes unfamiliar or they get confused [A9], but others do not identify anyone they would speak to for support with something online. In other cases the PWLD may not feel they need any support at all [A3].

*"I do it on my own, but **if I need any help I will ask my mum for some help"***
- Carl, post-probe interview, A8.

*"I do sometimes need a bit of help, sometimes I do it by myself, sometimes... **when I get stuck with something like searching things on google or Wikipedia, sometimes I do forgot so I get some help from my parents"***
- Tia, post-probe interview, A9.

***"I'm not sure*** *(if they know anyone to help them online) to be honest."*
- Bobby, Post-probe interview, A1.

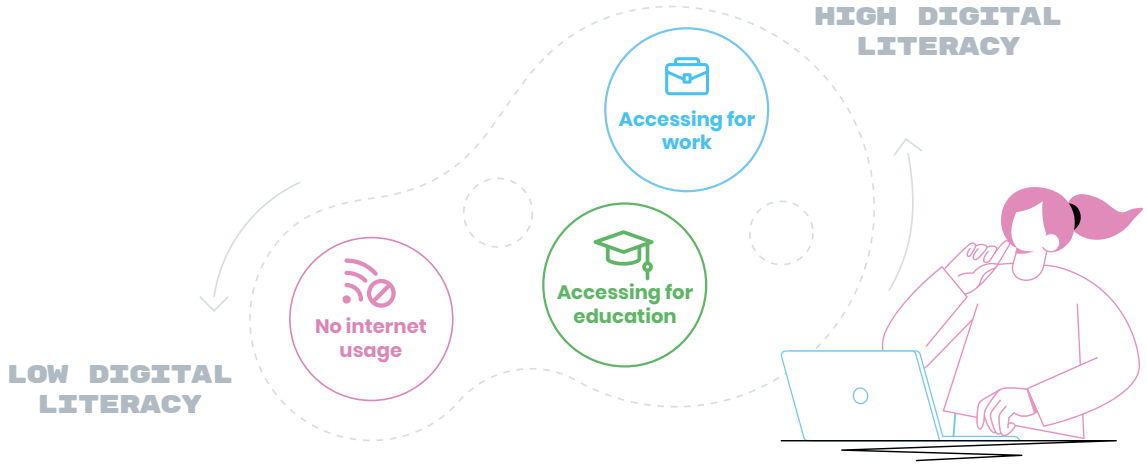
# *Outstanding questions*

1 How might we design a site that **reassures the anxiety that some PWLD feel?**

2 How might we balance reassurances that **the Mencap website is safe, with the anxiety caused by the inference that the internet isn't always safe?**

3 How might we **build confidence, to lower barriers in accessing digital?**

# What is the digital literacy of PWLD?




Confidence in ability and actual ability are two distinct but overlapping issues. A person who is put off by barriers that cause anxiety might otherwise be completely capable of using a website. Likewise, we could imagine the alternative, that a person might have the confidence to access a website without a supporter to help them, but on arrival find that the website is inaccessible and confusing.

Our participants reported using a wide range of different digital platforms, from Fitbits, to Netflix, to Google and looking up football results. One professional reported that her clients could use a self-checkout machine in a supermarket, but couldn't use a machine in a bank to deposit a cheque.

At one end of the scale, there are PWLD who don't access the internet at all, whether online or with a supporter. At the other end of the scale, there are PWLD who routinely access digital for work and education.

The breadth of digital literacy among PWLD is likely not far off the breadth of experience in the rest of the population.

Amongst the full UK population there are early tech adopters who quickly jump on new technologies and functions, and others who struggle and resist technological change. The difference for Mencap, is that the organisation chooses to pay more attention to people who are excluded.

Other organisations may take a cohort of end users and conduct interviews or online tasks focused on task completion, assuming a set of fairly homogenous behaviours amongst participants. With our research, we're fully aware of the diversity of people and voices that Mencap work with.

We see this research as a starting point – by working with PWLD we want to start to understand some of the challenges in digital and remove some of the barriers faced, but we know it will be a case of ongoing learning.

As we work with one cohort of research participants, it's possible that their digital literacy will grow as part of the experience, and we may need to recruit new participants to continue to learn, test and iterate.

# *Outstanding questions*

1 How might we **understand whether there are common "dealbreakers"** that prevent even people with high digital literacy from accessing a website easily?

2 How might we **reduce the complexity of a site to lower the bar in terms of access requirements?**

3 How might we understand whether **likelihood to complete a task online is due to accessibility barriers, or because the task in itself is too complex?**

4 How might we explore whether **complex tasks can/should be broken down into more manageable chunks**, to reduce accessibility barriers?

5 How might we review whether **the digital literacy of our research group has grown due to taking part in the project**, and recruit new participants moving forwards?

6 **How might we avoid creating 'accessible ghettos'** and instead embrace digital access for the wider digital population, not just PWLD'

# How important is human interaction when a PWLD needs

Across the board, from every mode of research that we carried out, **turning to a trusted person was the preferred method of accessing information**. For example, 57% of survey respondents gave this as their preferred means of finding information.

Further data shows us that this isn't just a matter of trust – the next most popular channel to access information is video (40%), which on the surface is the channel most similar to a face to face conversation.

Secondly, even when interviewing Mencap employees, all of whom had high levels of digital literacy and autonomy, they expressed a preference to speak to someone face to face rather than an email or written text, even when the person they are communicating with is the same in both scenarios. This demonstrates that it's the format, and not just the trust in the source that impacts the delivery.

In contrast, when asked “how do you prefer to learn things” only 40% of respondents selected “reading on the internet” and 28% “reading a printed leaflet”. However, it’s possible that understanding of the question “prefer to learn things” may not be understood consistently between participants (learning to play an instrument, attending a lesson at school or college, or finding out what time a train leaves could all be considered “learning things”).

There was some confusion in how respondents answered survey questions comparing video, audio and Easy Read formats, which makes comparing preferences between the three formats difficult. It is possible to say that video appears to be similar in popularity to Easy Read for displaying information amongst our survey respondents. One advantage of Easy Read over video, is that it is designed with a PWLD in mind, using clarity of language, short sentences, and visual cues. Across YouTube, videos created to teach something may not have these accessibility requirements in mind. It’s therefore possible that the format of video is preferred, but the accessibility requirements of Easy Read sometimes take priority over the preferred format.

Answering these questions is complicated. We can’t design a simple survey question or even a one-to-one interview that pulls apart the experience of difference content a person has consumed over their lifetime, that has led them to prefer one channel over another.

Even though face to face conversation, videos, and Easy Read were all spoken of highly of in terms of communicating information, two of our interviewees named Wikipedia as one of their favourite websites.

*"What is it about Wikipedia that makes it easier to understand?"*

***"it's just the writing, it's a lot of information"***
- Tia, Post-probe interview, A9.

We might think that lots of text would make Wikipedia less accessible, but it's possible that having one long page with all the information (little need to navigate to other pages) makes it a positive experience. It also makes use of sections and headings to help a user navigate the page – a format commonly used by websites communicating lots of information to the general population.

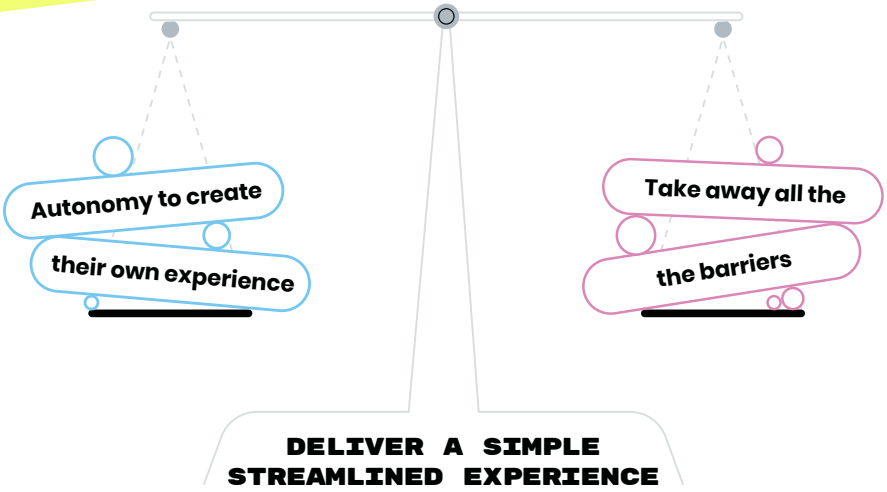
# Outstanding questions

1. How might we **separate communication channel preferences from accessibility of the content** within that channel when understanding which formats are preferred?

2. To what extent **should, and could, we design for unique user preferences?**

3. How might **we balance the simplicity of reducing need for navigation** by sharing as much information as possible up front with **the risk of overwhelming other visitors with too much information** in one go?

# Giving autonomy while allowing for gaps in awareness of need




Our research has found a diverse mix of communication preferences and accessibility needs. However, we need to be cautious about building a platform completely customisable to every possible need. Within our conversations with PWLD we often found that the person wasn't able to communicate their needs. Professionals working with PWLD advised that they might be able to tell us when something is difficult, but not necessarily why it's difficult, or be able to suggest improvements. Our interviews aligned with this.

*"He talked about how difficult it is to explain his experience.* ***His disability makes it hard to describe things, including his own experience.****"*
- Notes from 121 Mencap staff interview, Staff 2)

*"He often gives feedback on documents and things to make sure they're Easy Read. His preferred method is to sit with someone to read it though with him.* ***He's good at flagging if something is jargon or confusing, but not as good at suggesting alternative ways to express something. "***
- Notes from 121 Mencap staff interview, Staff 1)

When probed for information about what made websites more or less accessible, we struggled to extract this information from our participants. It may be that our wording was poor, and we needed to find another way to unlock this knowledge. However, knowing what we know about self-awareness of need, it's also likely that many PWLD are unable to determine these answers, even if the questions were phrased differently. Participants found it difficult to separate the purpose of a website from its format or design.

*"What do you like about those websites?"*

***"Well Amazon, you can get anything you want."***
- Carl, Post-probe interview, A8.

***Are there any websites that you don't think are very good?" [participant is confused] "Are there any bad websites, websites that you don't think are very good?"***

***"I don't really go on them. I don't go on ones that I'm not very interested in"***
- Tia, Post-probe interview, A9.

# Barriers to autonomy

Barriers to information such as log ins, or accepting cookies, or two factor authentication were flagged as making a website more inaccessible, and more anxiety-inducing. We need to make sure that setting format preferences doesn't present as an onerous or complex task, and acts as a further barrier to the website.

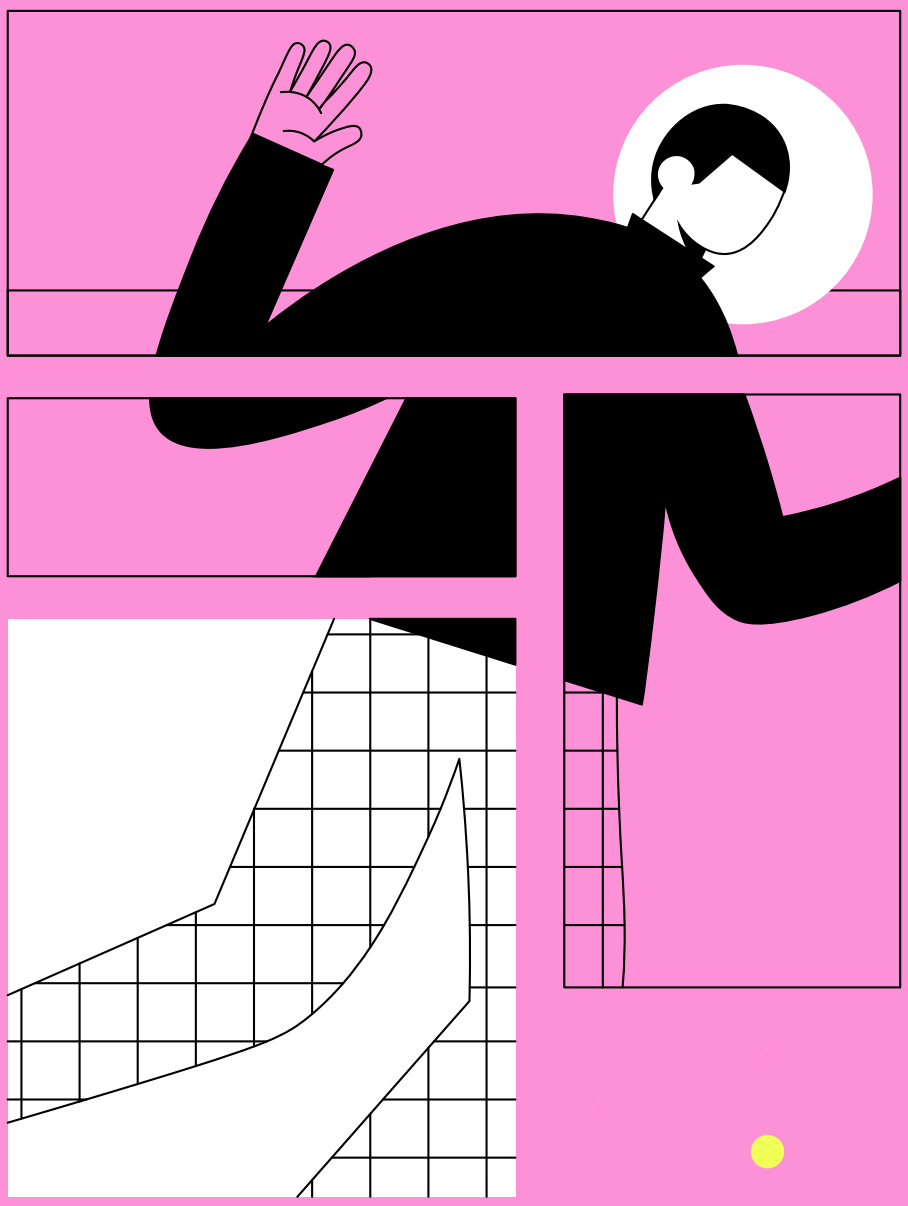
We also need to ensure that we aren't simply handing over the work of determining the most suitable formats to PWLD themselves, who may struggle to express or imagine what they prefer. Our role as researchers and designers is to filter out some of the complexity and cognitive burden, not to present an infinite number of options that leaves people lost and under pressure. We need to be cautious not to hand over the responsibility for delivering a positive and accessible experience to PWLD.

Our goal needs to be to provide a balance, to allow users to express some preferences as they go, but without expecting the person to arrive with a comprehensive picture of their needs, or any self-awareness of specific challenges they need to avoid.

*"(One of my clients) is not forthcoming,* ***she finds it difficult to explain what communication works for her.*** *But if you can identify things and then say to her, did you find this worked? Then she can say no or yes."*
*- Healthcare professional, B4*

One anecdote that brought to life the risk of relying on detailed self-awareness came up in our Exec conversations. We learned that internal staff, including PWLD voted that the new sex and relationships section of the website should be titled “let’s talk about it”.

Hypothetically if we reversed this, and asked PWLD what content they’d expect to see in a section of the website called “let’s talk about it”, it’s questionable whether they would be able to determine this. When we enter into co-design with PWLD, we should listen to their input, and give it the value it deserves, but we need to balance this contribution with our design expertise.



# *Outstanding questions*

1. How do we **alert visitors to alternative means or tools to view the website?**

2. How do we **remember what people choose without them getting "stuck" with their choice?**

3. How do we present options while **avoiding paralysis of choice** and feeling overwhelmed, or anxious about "getting it wrong"?

4. How do we factor in that **some people are less aware of their own needs?**

# The role of the Mencap website for PWLD

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Very few participants involved in this research reported using the Mencap website. The highest levels of usage were found in people who responded to the survey. This may be a biased sample as respondents were more likely to be more familiar with Mencap due to the fact they were recruited by Mencap to participate. Of these participants, 60% reported using the website "sometimes" or more often.

Mencap's goal is to make the UK the best possible place to live for people with a learning disability. Under this goal is a very wide remit, from challenging parliament, to offering one-to-one helpline support, to providing supported accommodation, to providing care workers, to sharing information and educating people about learning disability.

As discussed in the section above, one of the common barriers we discovered in understanding people's experiences, was that PWLD were not always able to express something that is missing. Answering a yes/no question is a lot simpler than being asked an open-ended question and needing to provide an unprompted response. Asking participants about how they find information is a very open ended question, requiring participants to comprehend the depth of what "information" could mean, and imagine situations where information might be lacking, and imagine what they might do in those situations. There are too many layers of complexity and lateral thinking required in the question to gain useful responses. Therefore, asking questions such as "why don't you go on the Mencap website", or "what might you like to see on the Mencap website" isn't straightforward.

When thinking about content and purpose, we may need to consider more distanced research methods, rather than our generally preferred approach of speaking directly with beneficiaries.

For example, when posing research questions such as “what are the key challenges in the lives of PWLD, and how can the website respond to these challenges?”, we may need to take a more lateral approach than asking the questions directly to the end users. Our research uncovered that PWLD generally turn to the trusted people in their lives, and those trusted people either turn to Google, or turn to the resources they’ve learnt are most useful over many years. If we can identify key moments that lead to a need to search for information, whether it’s the PWLD themselves, or a supporter in their life, we can look for ways to

1 Ensure that the **website responds to this need with relevant content**

2 **in an accessible format**

3 and look for ways to **help the website be found** in that moment.

Based on knowledge gained by working with other charities who have beneficiaries with life-long implications, and combining this with the keyword data we analysed, moments where support or information is needed might include:

- Early years support
- Accessing education
- Accessing benefits
- Accessing advice with personal finances
- Accommodation and living requirements
- Rights in the workplace and support tools

Under each of these topics could be a combination of signposting to trusted sites, or on-site content. Both signposting and on-site content should have the goal of explaining clearly what help is available and how to access it, as well as enabling time-poor carers and supporters to explain this to PWLD clearly and simply.

We need to explore whether presenting existing content in a more user-friendly and audience-cognizant way will help to surface that content and make it more usable. This might be through better design and layout, or through restricting the page into blocks of FAQs, bullet points, sub sections or videos. Rethinking the language so it's more user-focused may also help (e.g. "Talk to someone who can help you" over "Support").

The best way to present this information should be explored in the Design and UX phase of this project. We'd also recommend a full content strategy to explore the needs of these key life moments and how the website might respond in more detail.

# *Outstanding questions*

1 How might we **use design and UX to help the website fulfil its purpose?**

2 How might we **ensure that this content is findable?**

3 How might we **work with supporters and PWLD in co-designing this?**

4 How might we explore **whether changes in language can help accessibility?**

Although other areas of the website may also be of interest to PWLD, such as campaign work, or fundraising, focusing on the areas that deliver most direct value to the lives of the people Mencap champions will deliver the most impact.

# Carers and supporters of PWLD and their role in accessing digital

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your
dreams
happen

# What is the level of care that a supporter provides?

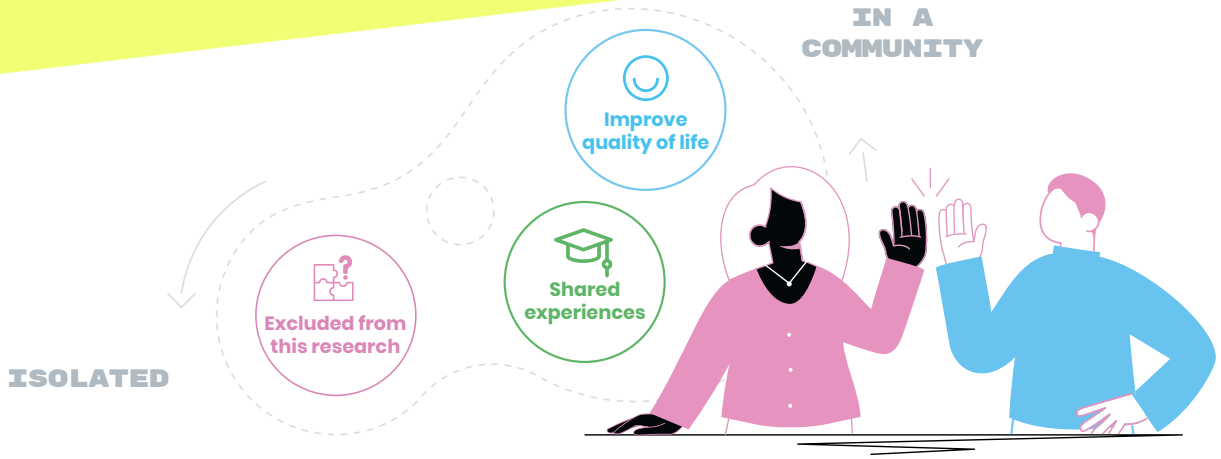
Our primary focus was on people with a learning disability, rather than their supporters. However, we appreciate that by supporting the circle around a person with a learning disability, we support the person too. Hypothetically, this might be through emotional support, as well as with information and advice.

We picked up nuggets of insight as to the daily lives of a supporter – one participant mentioned that by acting as a full time carer, she couldn't go back to work or she'd lose the benefits they received to support themselves. The tasks that we know that many PWLD don't take on themselves – the financial admin, booking tickets etc that weren't mentioned in how they use digital – we could assume that carers and supporters take on much of this admin themselves.

We know that a proportion of PWLD require support to access digital, and likely in other areas of their lives too. The amount of time this level of support requires appears to differ significantly, depending on how profoundly a person's learning disability affects their life. We heard on our Helpline calls that at least some supporters can spend a long time being passed between GPs, consultants, social workers, local authorities, accommodation managers and other types of professional who might be involved in a person's life. The more people involved, the more complex the situation, and the more time is likely to be required to resolving any difficulties.

We aren't able to put a number on level of support, or what proportion of supporters dedicate what amount of their time – all we do know is that it is likely that most supporters need to commit some level of time and resources into supporting a person with a living disability, and it's likely that the level of time and resources required is dependent on the extent to which the disability affects the person.

# How supported do carers and supporters feel in their role?



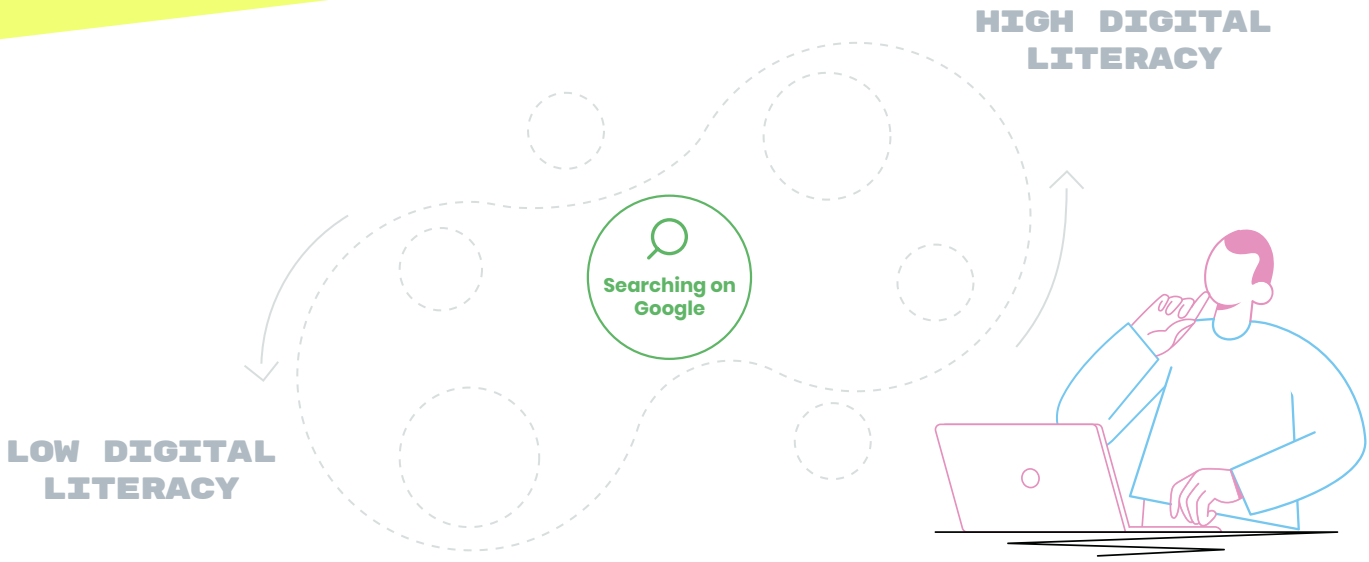

As described above, our level of insight in this area is less reliable. From the supporters who we spoke to, we found a theme that knowledge is acquired by chance, and the personal connections you make along the way are hugely important in your quality of life as a carer and supporter. This is factor we've seen mirrored in other charities – with often patchy communications between different organisations, knowing someone who's navigated those paths themselves is the best source of help you can find.

Unfortunately, those people who haven't found connections and support are more likely to have been excluded from this research, as our methods of recruitment relied on Mencap's existing contacts.

***"I learned more from parents than I learned from people really in the hospitals and stuff.*** *If you don't meet other parents, it's done for really."*
*- Judy, parent, post-probe interview, A5*

*"You can't then share your experiences with those people because they're all going through a completely different thing and* ***they're marvelling about what their child can do. You don't know if your child's even going to be able to do any of those things at all."***
*- Sonya, parent, post-probe interview, A4*

# How digitally literate are carers and supporters of PWLD?




As with the general population, the level of digital literacy is likely varied amongst supports of PWLD. Some carers and supporters have a learning disability themselves, or other access requirements.

> *"When Sol was younger, there were groups of people. Sometimes the people that I came across, they had learning disabilities themselves... And I think how difficult it must have been. Because* ***I felt quite able to for information because I don't have a learning disability myself."***
> *- Sonya, parent, post-probe interview, A4*

For those with an adequate level of digital literacy and confidence that they're using digital to aid their experience as a supporter of a PWLD, they're likely leaning heavily on Google.

The Helpline calls we listened to were very specific, making it difficult to simply design a page for every single circumstance that a PWLD could experience. Even amongst challenges that are common to large groups of people – such as starting secondary school – the information will differ between different local authorities, and may change from year to year in line with funding and grants.

Google can struggle to index this kind of local content effectively, adding another challenge into the mix for a supporter trying to find the information they need. This means that higher than average levels of digital literacy may be needed to uncover the answer to a question.

***"It is hard to locate the activities available to my learning-disabled sister through our local council.*** *Her social worker is uninformed and hard to get hold of. Perhaps more* ***information of local services would be useful on the Mencap website,*** *however, that might take the responsibility away from the council to reach out to disabled people in their borough/region."*
- Survey response to question 'What would make the Mencap website more useful for you'?

One challenge is that Mencap isn't front of mind as a website to look at when seeking information. Accessing the information on the Mencap website is not purely down to level of digital literacy but - does the information exist on the site to be found in the first place, or is too local/niche a question? And if it is, is Google surfacing it effectively when a person searches?

Assuming the information is on the website, there are two options to consider. Either improving Mencap's SEO, and likelihood to be found in search, or, improving unprompted brand consideration, and driving more people to the site directly in the first place. Pursuing a marketing strategy in line with either or both of these approaches would be required to help people use the website more, irrespective of their level of digital literacy.

*"I've trawled the Internet looking for advice... I've dealt with various organizations...* ***I always feel I'm in a bit of a black hole with of constantly encountering challenges."***
*- Sonya, parent, post-probe interview, A4*

# Designing for all

Barriers to information such as log ins, or accepting cookies, or two factor authentication were flagged as making a website more inaccessible, and more anxiety-inducing. We need to make sure that setting format preferences doesn't present as an onerous or complex task, and acts as a further barrier to the website. We also need to ensure that we aren't simply handing over the work of determining the most suitable formats to PWLD themselves, who may struggle to express or imagine what they prefer. Our role as researchers and designers is to filter out some of the complexity and cognitive burden, not to present an infinite number of options that leaves people lost and under pressure. We need to be cautious not to hand over the responsibility for delivering a positive and accessible experience to PWLD.

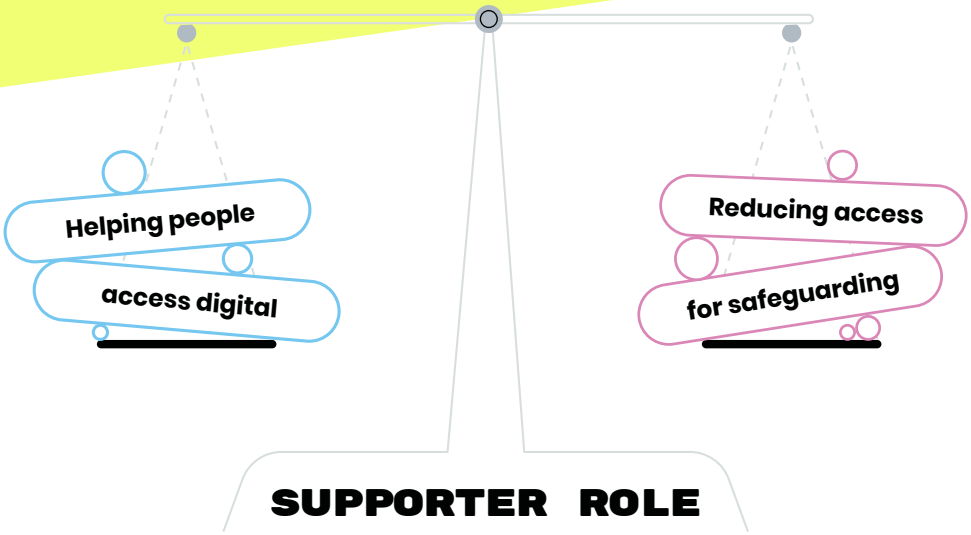
Our goal needs to be to provide a balance, to allow users to express some preferences as they go, but without expecting the person to arrive with a comprehensive picture of their needs, or any self-awareness of specific challenges they need to avoid.

*"Photosymbols are what people use but it's not attractive from an aesthetic perspective.* ***It screams 'I am disabled' rather than 'I am enabled"***
*- Exec Interview*

# *Outstanding question*

How might we **create accessibility options that appeal to all, and look and feel stylish** and attractive, without "feeling disabled" and ostracizing?

# What is the balance between enabling access and reducing access e.g. for safeguarding?




Most of our conversations suggested that carers, professionals and parents play the role of enablers rather than gatekeepers. We didn't uncover any stories of PWLD being restricted in what they do online, aside from minor barriers in safeguarding, such as ensuring social media accounts are private, or stepping in to complete the final transaction on a shopping site.

It should be noted, that if any supporters do deliberately put barriers in place to restrict the activity of PWLD, it's unlikely that our research would have reached these people.

With what we've found, we can continue with the assumption that the chosen role of a supporter is to enable as much access as possible, whilst trying to mitigate general risks of going online.

*"Sometimes my mum puts my account on private on Facebook, Instagram or TikTok...* ***I feel a lot safer if I get help from my parents... I feel a bit safe on Google but sometimes I don't and I get some help from my parents"***
- Tia, post-probe-interview, A9

# The role of the website for supporters

## Emotional Support

Our experiences in speaking with supporters indicates that acting as a carer or supporter can feel very isolating, in that other people in your life don't understand the challenges you have. As we discussed earlier, it appears to be only luck that connects a person with a supportive community, or not.

- Can the website play this missing role of a friend, rather than leaving it down to luck?
- Can the website reduce feelings of isolation, or at least offer a positive emotional experience?

By understanding the common moments where a person is likely to seek support, the pages they're likely to land on, and what their needs are likely to be in that moment, we may be able to design an "onboarding" experience with Mencap, that leads them to come back to the website again, the next time they need information or support.

> ***"You do go through a grieving process whether you like it or not...*** *because the child that you thought you had, you haven't got, you've got something different... And takes quite a lot of getting your head around. And I think there should be a lot more support for that at the start."*
> *- Judy, parent, post-probe interview, A5*

# Factual Support

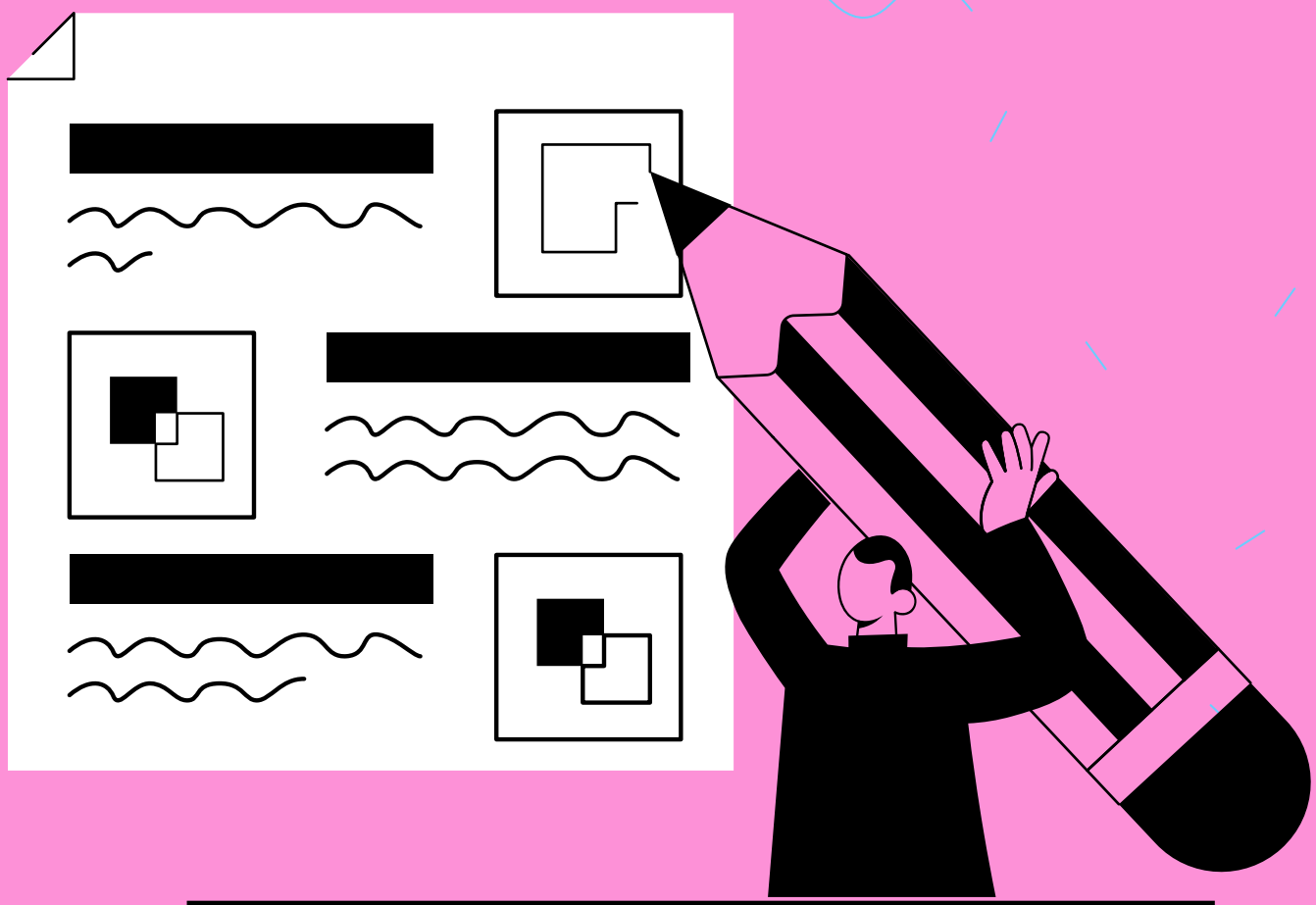
It's unrealistic that the website can answer every query that a person has, due to the level of detail and complexity of individual circumstances, and the ever-changing variances between local authorities. However, that's not to say that the website can't help a person to "search better". Strong signposting to other resources, summarising general processes or different individuals and bodies involved, advice on terminology and how to look for what you may be entitled to could all reduce the time a supporter spends seeking answers online.

Our research with other charities has found that carers often don't realise they could have applied for support until after that kind of support could have been relevant. If the Mencap website can deliver a positive experience that aids how a supporter searches and looks for information, it can play an important and supportive role without having to store the specific information itself.

# *Outstanding questions*

1 How might we design a website that **fills the gap in social and/or emotional support that some supporters lack?**

2 How might the website **facilitate an improved online experience for supporters of PWLD**, even if it can't answer every question directly?



# Accesibility Guidelines

We're not going to define which content is most important to make accessible as part of this work. Physical accessibility guidelines like WCAG are not likely to be comparable.

Instead, we hope to define a set of principles for consideration in design, the beginnings of which can be found in the next section. At this moment, we don't yet have enough information to define the format of these principles. We may be able to create a checklist to mark off, a list to score against, or a design approach to follow.

What we're not fully likely to do as part of this work is define which content themes are more important than others in making accessible. If it's not possible to implement our accessibility and design recommendations across the whole website, an approach will need to be defined as to what content themes to focus on.

Below we have summaries our findings to date, as well as areas of further research that we have identified. These areas of research will be picked up in the Design and UX phase wherever possible.

# Questions on approach:

- How might we involve PWLD in codesign and testing?
- How might we consider the needs of people without a learning disability, but who may also have accessibility needs, such as older people or professionals who aren't tech savvy?

# Findings so far

## Device usage

The research we have conducted so far suggests that mobile is the preferred device. The survey results indicated that 56% of respondents access the internet using a mobile. Google Analytics supports this finding, with the majority of visitors on mobile devices. Both sources show that usage of mobile does appear to be slightly lower than we'd see in the general population, but it's still more popular than computers and laptops.

## Familiarity in User Interface

Certain websites and platforms were mentioned again and again. It would make sense therefore, not to reinvent the wheel with navigation that differs too much from how users already successfully navigate the most popular platforms – YouTube being particularly commonly mentioned. However, just because a platform is commonly used, doesn't mean it's the most accessible – content and visibility could be playing just as big a role in share of voice.

Working with PWLD in a co-design approach to understand how they use these platforms may be of value. We also need to be conscious of a potential lack of awareness in need – a person may use a website frequently but not be able to express why they only use it for certain tasks and not others.

# Emotion

Knowing that anxiety can surface when PWLD access unknown situations, or complicated situations, designing a website that feels calm, and quiet could be of benefit.

For supporters of PWLD, creating a sense of emotional support could be beneficial in building a long term relationship with the brand where there isn't always one currently.

The moments in a person's life where they search for information about or in aid of learning disability are likely to be moments of high emotions – struggles with finance, housing, education, or diagnosis can lead to agitation, anxiety and panic, which will all impact how we complete a task. When things are smooth and going well with little change, there's less need to search for new information. The possibility of heightened emotions should therefore be considered in design.

**How might we consider the effects of emotion on user behaviour in our design?**

# Defining accessibility

WCAG guidelines for accessibility are able to define specific levels of contrast or font size to ensure that a website is friendly to people with a disability. In an ideal world, we would also be able to provide a yes/no list of guidelines where a person can objectively identify a "pass" or "fail". Unfortunately, it's unlikely to be this simple. Different people's access needs differ so widely, as does the extent to which a learning disability can impact on a person's life.

In the past, people have tried to define texts by reading age using specific values, such as number of syllables in a word, and number of ideas or words per sentence. This approach to defining reading age and level of difficulty of a text isn't widely accepted though. It's likely that our approach will be similar – there are too many variables as to what makes something challenging or not challenging for a person to comprehend to define a baseline standard.

However, it's not difficult to imagine a piece of information that would definitely be completely inaccessible to many, and perhaps a piece of information that would be very accessible to many. With this in mind, it may be possible to define dealbreakers or minimum standards to adhere to.

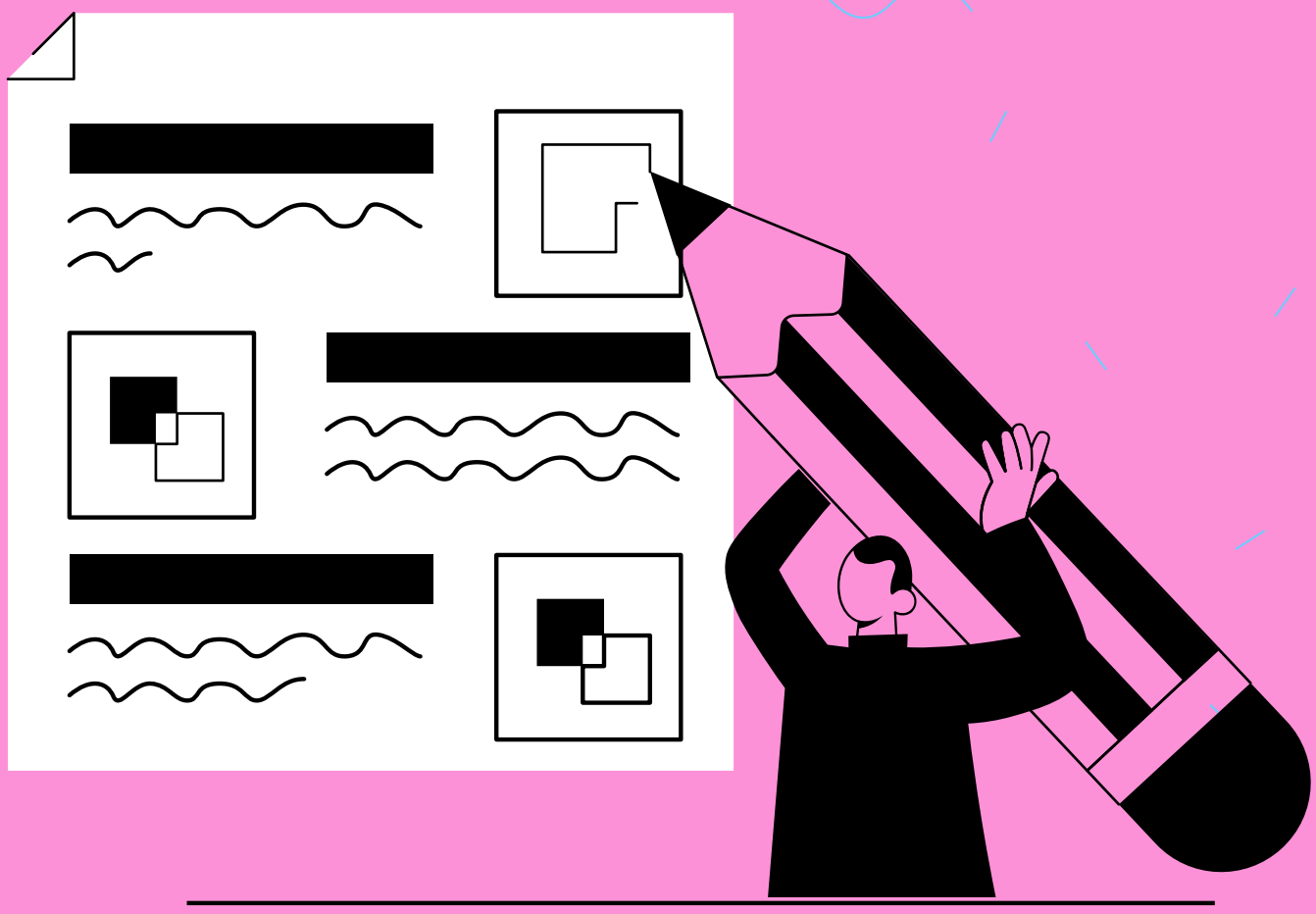
**How might we identify if there are base level requirements that we can define, such as "one idea per sentence", or dealbreakers such as "never use a font size smaller than X"**

**How might we consider Mencap's existing guidance into creating Easy Read documentation in these guidelines?**

# Format

Our research so far has suggested that Easy Read and video are both popular formats for learning information. We aren't yet able to define the best way to incorporate either of these modes of communication into a website. We also aren't able to say whether both are necessary – perhaps everyone who likes video also likes Easy Read, and people who dislike video also dislike Easy Read? Adding more and more modes of communication doesn't necessarily mean opening up accessibility to more and more people.

**How might we identify which modes of communication make information accessible to the most people, with the least effort to implement?**



# Rough principles to guide the next phase

As described already, these are an initial framing of principles only, likely to change significantly as we continue our research. At this point, **we envisage them as living guidelines**, likely to continue to change as we learn, iterate, and encompass learnings from others.

If validated and incorporated into our accessibility recommendations, we'd also like to share the "why" behind the principles, so that other organisations following them can understand the context of each recommendation. Ensuring that the guidelines in themselves are accessible, understandable, and persuasive will help build a better digital experience for PWLD as a whole.

At this stage, these principles stand as directions to explore as we enter the design phase.

# 1. Reduce task complexity

Every person with learning disability is different. Each person will have different skillsets in different areas, as well as varying levels of competence and confidence in their own skills. Informally, the belief is that learning disability is often compounded by mental health challenges, potentially due to a lifetime of lack of support and appropriate resource. However, because mental health diagnoses and definitions are biased towards people without a learning disability, the scientific community hasn't proven or disproven this widely held belief. Secondly, levels of stress, anxiety and burnout amongst carers is thought to be higher than the general population. This points to a need to consider the impact of anxiety and stress when designing user journeys and page layout.

Our conversations with PWLD, supporters and professionals in the field, have begun to shed light on the cascading chain of events that can happen as a task becomes more complex:

- **Environment** - More people tend to be involved in completion of a task
- **Duration** - More time is required to complete the task
- **Cognitive load** - More decision making is involved in completing the task
- **Anxiety** - More anxiety is triggered at the thought of completing the task
- **Resources** - More support is required to complete the task
- **Accessibility** - More barriers in accessibility start to appear, presenting more challenges in completing the

This leads to…

- More people try, but fail in completing the task
- More people don't try to complete the task in the first place

Some of the above we cannot change – we can't stipulate how the DWP processes PIP applications, for example. But we may be able to reframe even a task like this to make at least some of it more accessible and more manageable.

For example, in cognitive behavioural therapy (CBT), therapists advise on breaking overwhelming tasks into small chunks to make them more manageable for people with anxiety. On completion of each step of a task, a person feels a sense of satisfaction at completion of that step, and it increases their confidence and drive at approaching the next step.

We could take these same principles and apply them to how support is presented on the Mencap website. When support is offered, rather than simply signposting a link, the steps for the completion of the task should be broken down into small manageable chunks. All of this boils down to a need to do clear and simple well. We could explore more demonstrative wording, such as "Tell me information about what benefits I might be entitled to" rather than "financial support".

**How might we…**

- Reduce the number of people involved in completing a task
- Reduce the feeling of a task taking a long and overwhelming amount of time
- Reduce the cognitive load of decision making
- Reduce anxiety surrounding a task
- Reduce the support required in completing a task
- Reduce the accessibility barriers to completing a task

Even if we can't tackle all of these principles, by improving a handful of them is likely to move the barrier to task completion to such an extent, that a greater proportion of PWLD and supporters are able to complete a task successfully.

*"It does ask me sometimes different things, but I don't know about, so what I do is,* ***I don't go on it... I'll leave the site."***
*- Tia, post-probe interview, A9*

*"It's like the first multidisciplinary meeting I had to go to at his school. I've never been to a meeting with all these health professionals before.* ***Frightened to death, little old me, you know, thinking what the hell have I coming here? It's so scary."***
*- Judy, parent, post-probe interview A5*

*Everyone is so different but I'm trying to gauge on my clients,* ***a lot of them struggle around technology, they find it scary and intimidating,*** *they ask us to break it down."*
*- Healthcare professional, B6*

# 2. Rely on trust and familiarity

WCAG research suggests that PWLD can take time to get used to new tools and environments. Leveraging UI and design principles that they are familiar with will likely help them to get started with a site for the first time, even if they haven't visited it before. Through speaking to participants, it's clear that the most commonly used platforms amongst the general UK population are also the most popular platforms for PWLD, such as YouTube. Using recognisable design and navigation from these platforms will reduce the anxiety associated with having to learn to navigate a new platform, and ease the cognitive burden that could act as a barrier to using that service or platform.

- How might we identify the most accessible elements of popular platforms?
- Are there specific elements of design and navigation that make these platforms more popular – or are they just the market leaders in the entertainment formats they deliver?
- How might we replicate or be inspired by familiar design elements in our design?

# 3. Improve digital literacy of PWLD

## Mencap's goal to make the UK a better place to live as a PWLD

Mencap's vision is to make the UK the best place to live for a person with a learning disability. Within this vision falls the creation of accessibility guidelines, in the hope that other organisations will take them on, and ultimately make more services and platforms accessible to PWLD. Another means to achieve this goal would be to improve the digital literacy of PWLD, so that we are not reliant on the resources, drive and efforts of other organisations to make a change – instead, could we provide a means to improve the digital literacy of PWLD? Rather than waiting to see if other organisations choose to implement this advice, individual PWLD could be empowered to widen their skills and open up their own digital experience.

From speaking to supporters of young people with a learning disability, there's anecdotal suggestions that different people experience different levels of educational support.

*"Sol is in [a] school that caters for every kind of learning disability, which may be then means that there are a bit less flexible... The school were quite reluctant, because they thought there was no point in him learning to read because they said they didn't actually understand what was what was happening in the story... but because he can read and because he's taught himself to spell, he can then make choices.* ***So on an online world it's great, because if he finds something he likes, then he can retrieve it again****... Words and writing give him a lot of pleasure in life****"***
*- Sonya, parent, post-probe interview A4*

*"If there's any cause and effect [games] that people could go on and [for example] burst balloons... and there's all sorts of apps now aren't there that you can go on that. Things like that I think would be really lovely.... It'd be wonderful for the parents...* ***anything that communicates parents with the child if they're nonverbal is amazing."***
*- Judy, parent, post-probe interview A5*

One supporter suggested that helping them to understand social platforms would help them to help the people they support to use it:

*"For things like Instagram and TikTok, because I don't use them, I would like to have support, to understand what it is, what it does, what is the purpose of it... **So someone could take time with me so that I can understand it."***
*- Mahmoud, post-probe interview, A7*

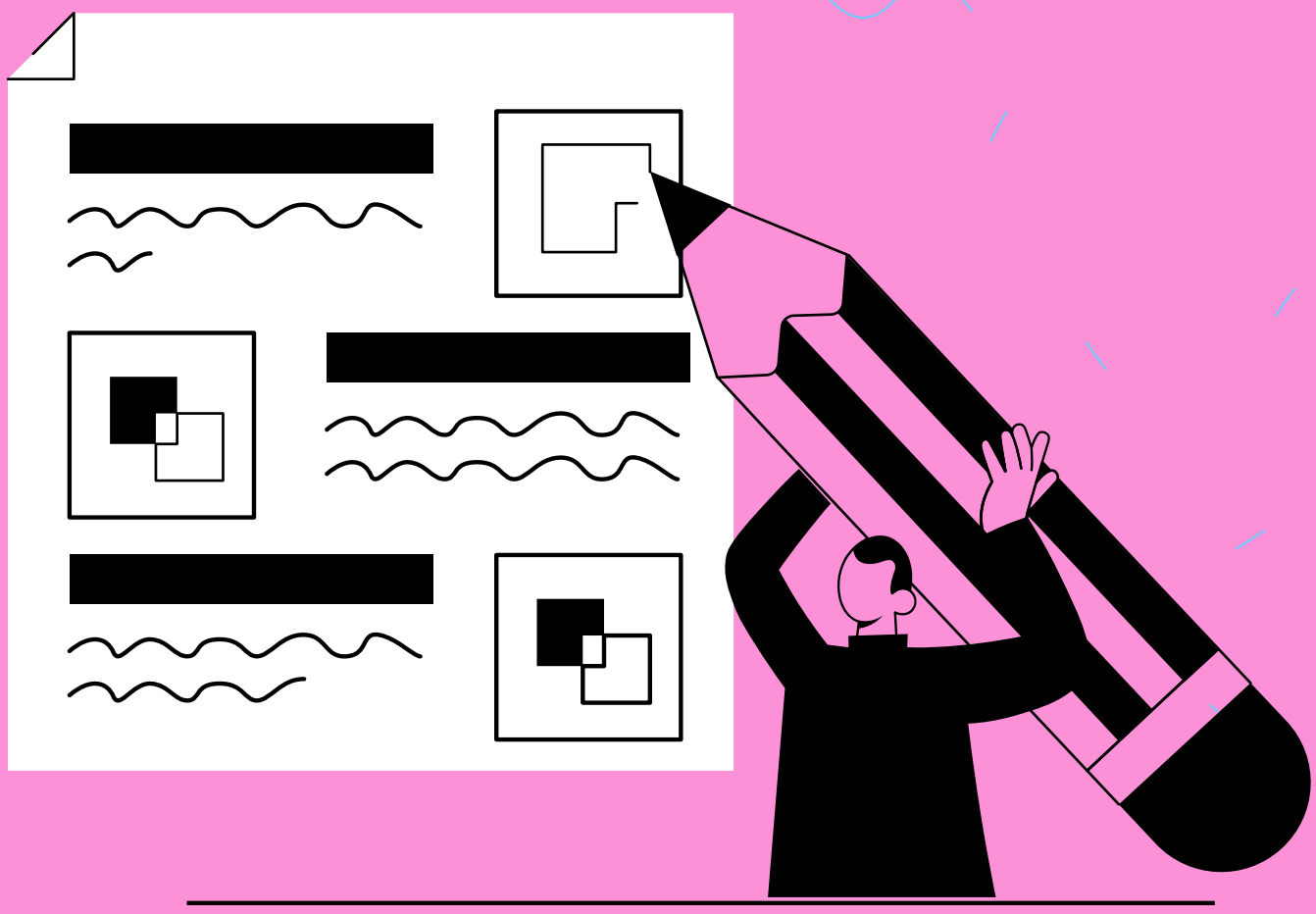
*These three quotes above all point to a desire among supporters that equipping them the right resources and materials would in turn open up the digital experiences of the people they support.*

- *How might the Mencap website best support the learning and development of users, which could help people to access content more easily on other websites? Is there any content like this that already exists within the Mencap website?*
- *How might we co-design with participants who have different accessibility preferences and requirements?*
- *How might we facilitate PWLD to explore preferred modes of communication, such as an area of the website where you can play with the accessibility tools?*
- *How might the website serve to improve the digital literacy of its users?*

# Improve digital literacy of supporters

Aside from how PWLD are impacted by lower levels of digital literacy, there are other audiences within their sphere of influence who may also benefit from improved digital literacy. For example, older parents who are less confident with accessing the internet via mobile devices. There is also anxiety among professionals using technology - how can we improve their accessibility too, which is in turn likely to benefit people with more profound learning disabilities, who require support workers?

***"There are a lot of support workers, really good support workers who have been around a very long time, say I didn't come into this job to use computers,*** *but to work with people. We've got a lot of experienced people that we lose."*
*- Healthcare professional, B4*



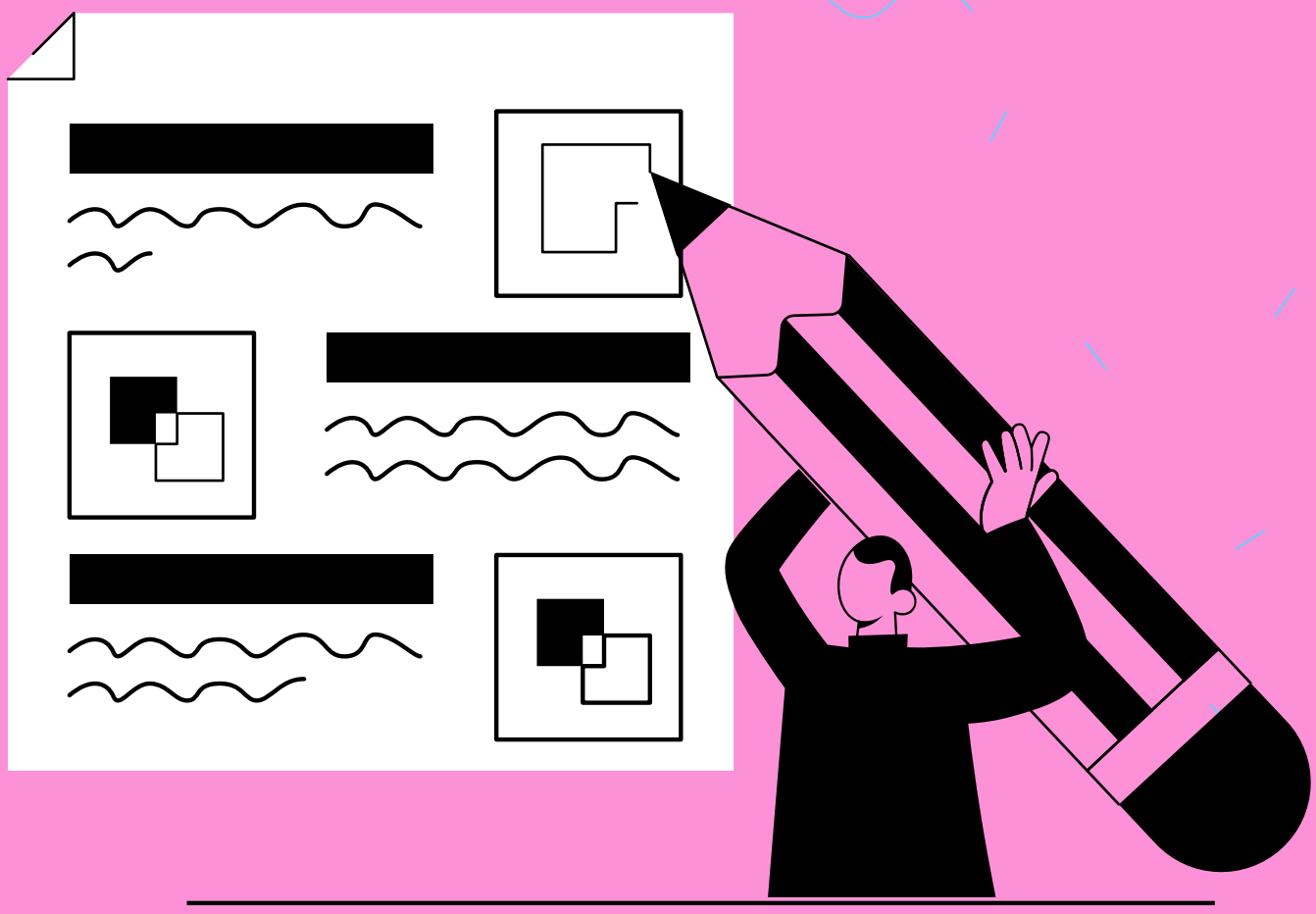
# WCAG objectives in designing for PWLD

The W3C who produce the commonly used WCAG web standards guidelines has defined eight objectives for designing content for PWLD.

Each objective is backed up with specific advice, persona research and user stories. The eight principles are:

- Help users understand what things are and how to use them
- Help users find what they need
- Use clear and understandable content
- Help users avoid mistakes and know how to correct them
- Help users focus
- Ensure processes do not rely on memory
- Provide help and support
- Support adaptation and personalisation

We will use and build on these objectives in our own website design.



# Design activities and facilitation of codesign

Overall, we found a positive response to the concept of co-design.

***"Knowing that you guys want to do more for people with learning difficulties... it's, like, really good."***."
*- Bobby, Post-probe interview, A1*

***"I mean, I actually really liked doing it because sometimes when you've got a child with learning disabilities life is very routine and Sol often has quite limited interests. And actually it was a nice thing to do with him just making the videos."***
*- Sonya, parent, post-probe interview A4*

# Awareness of need

As we enter into co-design and other design and UX activities, we need to keep in mind that not all participants will have awareness of their own needs. Participants might say they don't like something, but they may not be able to express why, or suggest what would be better. We need to remember this when designing tasks and activities.

We also found that some PWLD struggled to separate their perception of content of a website from the structure and navigation of a website. We need to be clear in how we approach activities that the content of any mock ups or activities doesn't influence how participants respond to design.

**In our research, how do we ensure that our participants and contributors are truly focused on design, and not on content or purpose?**

# Social model of disability

Following Mencap's advice, we have used a social model of learning disability, not medical. This means that at no point have we asked participants about any specific diagnoses. We have only asked questions about their experiences.  We will continue to follow this approach for the design and UX phase, aiming for a spread of experiences with some people more mildly affected by learning disability, and others more profoundly affected.

Using this model avoids "putting people into boxes". We should be aware though that it can mean it's more difficult to ensure we have a spread of experiences across the board, and we could be at risk of working with people who are more similar to each other.

# Notes

**Existing advice and guidance:**

NHS England: https://www.england.nhs.uk/wp-content/uploads/2018/06/LearningDisabilityAccessCommsGuidance.pdf

CHANGE: https://www.changepeople.org/getmedia/923a6399-c13f-418c-bb29-051413f7e3a3/How-to-make-info-accessible-guide-2016-Final

W3 Guidelines: https://www.w3.org/TR/coga-usable/