Our right to be techy!
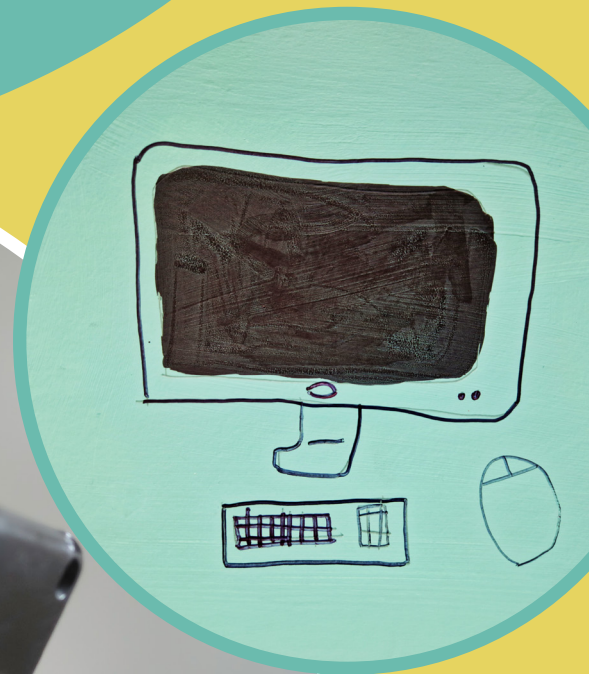
Making digital transformation transformative for people with learning disabilities in Scotland

SCLD

TEC Technology Enabled Care

Scottish Government
Riaghaltas na h-Alba
gov.scot

People First
(Scotland)

Acknowledgements

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Dedication

This report is dedicated to Jack McBride, a young man who loved life, and digital technology. Special thanks go to Annmarie and John McBride, Jack's parents, who were able to tell us about the impact of technology on Jack's life.

A word from the Digital Navigator Board

"I think it's especially important to have this report to understand how digital can work for people with a learning disability."
John Clarke

"Everyone deserves to have equal access to learn about technology, even if we learn 1 to 1 and not in a large classroom it is still important for people with learning disabilities to have an equal access to this type of learning. We may even become better at technology than others without our learning disabilities, with the right training!"
Lindsay Kinloch

"I think the report is important to people with learning disabilities because it is useful for people who may not understand what we mean by digital and some of us may not know how to use software and technology. We all learn in completely different ways."
Leeanne Clark

"The report is very important for the digital skill development of people with learning disabilities and their families."
Khoukha Nacef

"This report is important because Louis has the same right as everyone else to keep in contact with his loved ones and to socialise with his peers through social media. It is imperative for his wellbeing that he is empowered to do so."
Sarah-Louise Slater

"I hope this report shows that people with learning disabilities can get online, and how they can be supported to use technology. It sounds boring but we've been trying for so long and still haven't got digital inclusion right! We CAN make it accessible and inclusive for all."
Aaron Hume

"We need to make sure that technology works for people as easily as a light switch!"
Sandy Stark

Executive summary

Background

In 2022, SCLD was funded through the Scottish Government Technology Enabled Care (TEC) social care programme, to consider how digital technology might transform the lives of people with learning disabilities. Digital exclusion is just one of many ways people with learning disabilities are excluded from society, and this is mirrored in the lack of investment in learning disability specific specialist technologies. The Covid-19 pandemic increased the rate of technology use exponentially, but if developments are not designed to address the needs of those who are already digitally excluded, they run the risk of furthering the digital divide.

It is in this context that this project looked to understand how people with learning disabilities were engaging with technologies already, and what types of technologies would be effective and needed both within health and social care, and in the wider digital landscape, to give people more independence, choice, and control, and to transform their lives for the better.

Research methods

The project took a participatory action research approach. The project was steered by a lived experience board known as the Digital Navigator Board, 11 of whom were trained as co-researchers on the project.

The primary research was undertaken using a qualitative approach, comprising semi-structured focus groups and self-complete surveys. This consisted of four co-researcher-led focus groups with the Board members' peer networks and a further four focus groups undertaken by People First (Scotland), and 16 surveys. A total of 114 participants fed in their views to the project.

Research findings

Several themes were uncovered in the research.

Increasing consumer technology use since Covid-19: Participants reported enhanced confidence and skills, particularly in the use of communication platforms like Zoom, and social media such as Facebook and WhatsApp. Various digital devices and applications were embraced, with voice-controlled devices offering useful benefits for some.

Positive impact of digital technology: This was evident in improved communication, connection with friends and family, and increased independence. Participants highlighted the transformative effect on quality of life, confidence, and choice. Digital tools, from reminders to assistive apps, contributed to personal safety, independence and autonomy.

Challenges, barriers and fears over online safety: Participants faced difficulties with app complexity, security measures, connectivity, and affordability. Frustrations arose when technology malfunctioned, and concerns about online safety, cyberbullying, and potential scams were widespread. The financial implications of technology, including costs of internet access and devices, posed barriers for many.

Facilitators to accessing digital technology, and the role of staff and support: Skills and confidence played a pivotal role, often acquired through training and practice. The role of supporters, both family and staff, was paramount in assisting individuals to navigate digital spaces effectively. The need for improved digital skills among supporters emerged as a recurring theme.

Limited use of specialist technologies: Few participants had experience of using specialist technology, with those who did mainly utilising relatively old-fashioned telecare services. People did mention other apps, such as PAMIS digital passports, and other assistive communication devices such as speech to text software, but concerns over privacy, cost and worries that technology enabled care would lead to fewer support staff, remained.

Moving forward, addressing these challenges and enhancing digital accessibility alongside innovations in health and care technology will be crucial in ensuring that the potential benefits of digital technology are fully realised for people with learning disabilities in Scotland.

Recommendations for moving forward

Given everything that we already know about the lives of people with learning disabilities, what we have learned as part of this project, and taking account of the Scottish Government's priorities set out in the Digital Health and Care Strategy, SCLD believes there are a number of recommendations that will help bolster digital inclusion and promote digital solutions for people with learning disabilities in the short to medium term.
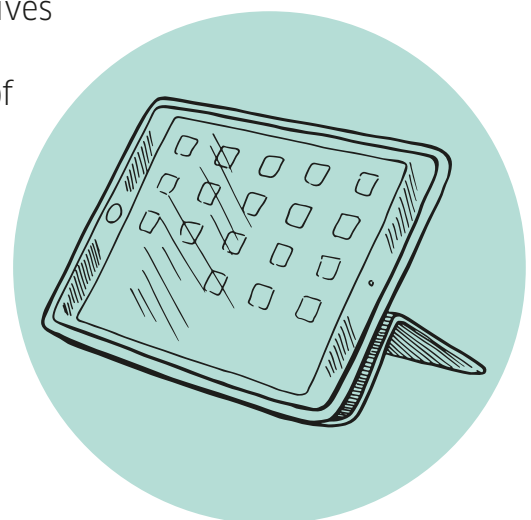
Recommendation 1: The Scottish Government should provide funding for learning disability digital inclusion coordinators across Scotland. Their role will be to bring together networks dedicated to finding person-centred solutions to digital exclusion and promoting digital technology and participation for people with learning disabilities.

Recommendation 2: The Scottish Government should provide funding for a learning disability lived experience board focused on digital health and social care services and technologies. The Board would provide expertise at every stage of the design and delivery of digital services and solutions that will impact on them.

Recommendation 3: The Scottish Government should support a co-produced learning disability pathfinder project utilising personal data stores to empower people to interact with health and social care services. This pathfinder must include experts by experience, organisations with experience of co-producing such initiatives with people with learning disabilities and be supported by an organisation with expertise in health and social care innovation.

Recommendation 4: The Scottish Government, Public Health Scotland and NHS Boards must ensure a joint approach, with adequate resources, to learning disability data improvement. This will support fair and equitable health and social care outcomes and lay the groundwork for success in the Scottish Government's strategic priorities across digital health and social care.

Concluding comments

For any change to be truly transformative, wholesale cultural change is needed. The health and social care sector, and society in general, need to see people with learning disabilities as more than service users. It is imperative we spark a cultural change whereby stakeholders are committed to encourage people with learning disabilities to explore and independently use technology, with appropriate measures in place to ensure people can make informed choices about its use. As the transition towards a digital society continues apace, now is the time to make sure that no one, including people with learning disabilities, is left behind.

Contents

Introduction and methods

Background and policy context

The 21st century has seen a paradigm shift in the use of digital technology across all aspects of life in Scotland. From the rise in smartphone usage and the proliferation of digital platforms, to the use of transformative technologies across health and social care, digital tools now permeate every facet of society. However, while digital technology has provided countless opportunities, it has also inadvertently widened the pre-existing digital divide, leaving behind some marginalised communities, including people with learning disabilities.

> " Although the UNCRPD promotes access to the internet as a human right, people with learning disabilities are at particular risk of being digitally excluded. "

Indeed, lack of access to the internet, and digital technologies generally, is one in a long list of ways in which people with learning disabilities are excluded from society. Although the United Nations' Convention on the Rights of Persons with Disabilities promotes access to the internet as a human right (UNCRPD 2006), we know that people with learning disabilities are at particular risk of being digitally excluded (Chadwick et al. 2022). It is telling that in **The keys to life** (Scottish Government 2013) the only mention of digital technology is to recognise that people with learning disabilities require support to identify when they are being groomed on social media.

It is beyond doubt that since March 2020, when the UK went into lockdown due to the Covid-19 pandemic, the use of digital technology has increased exponentially. The Connecting Scotland initiative, set up in the wake of the pandemic, aimed to provide devices, connectivity and training to digitally excluded households, so they could stay connected to friends and family, as well as access public health advice (Connecting Scotland 2020). As digital technologies advance at an even more accelerated pace, developments must be consciously designed to address the needs of those who are already digitally excluded, including people with learning disabilities, or they run the risk of furthering the digital divide that already exists.

The barriers that exist when it comes to accessing the internet are well documented. These include financial barriers, societal attitudes, lack of policy or governmental support, lack of education and training and lack of consideration of individual support needs when designing ways to interact online (Chadwick et al. 2013). Interestingly, although for some people the necessity generated by the Covid-19 pandemic led to increased digital participation, an academic review identified the

same barriers to access, and little evidence that those who were digitally excluded pre pandemic were now digitally included (Chadwick et al. 2022).

The digital exclusion experienced by people with learning disabilities is mirrored in the lack of investment in learning disability specific specialist technologies. The last few years have seen huge leaps forward in digital technologies and solutions across health and social care, including adaptations in consumer technology aimed at helping people to live more independent lives. However, a recent review of the learning disability technology landscape in England (Bloomfield and Villa 2021) found significant underinvestment in learning disability specific technology, much of which is poorly adapted from use with the elderly population. The review also highlighted that much development in this area has been driven by support workers and family carers, with little being done to understand what people with learning disabilities themselves want and need. If nothing is done to address this, there is a very real risk that technology will continue to reproduce and exacerbate existing inequalities rather than offer solutions.

> " A recent review of the learning disability technology landscape in England found significant underinvestment in learning disability specific technology. "

Both learning disability specific policies and wider digital health and social care policy recognise the need for digital inclusion for everyone. Through its Towards Transformation Plan (Scottish Government 2021a) the Scottish Government has committed to improve digital access for people with learning disabilities so they can stay connected to their friends, family and communities. Scotland's Digital Health and Care Strategy (Scottish Government 2021b) also includes a commitment to promote digital inclusion by recognising the diversity of Scotland's people and their accessibility needs. However, it will require a concerted effort to make these policy aims a reality.

It is in this context that it is imperative we engage with people with learning disabilities to understand how they are using technologies already, what types of technologies would be effective and needed both within health and social care, and in the wider digital landscape, to give people more independence, choice, and control, and to transform their lives for the better.
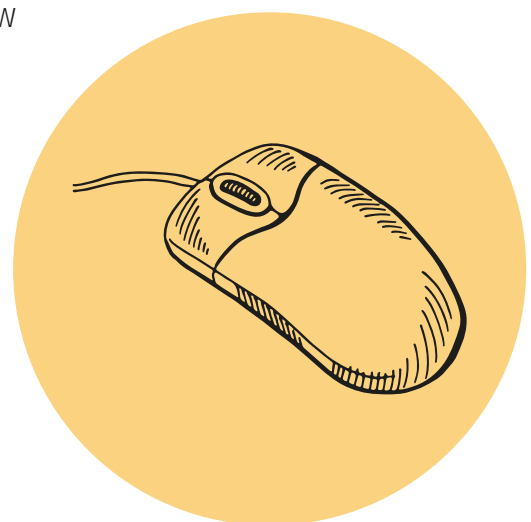
Technology Enabled Care programme funding

In 2022, SCLD was funded through the Scottish Government Technology Enabled Care (TEC) digital social care programme, to consider what digital transformation means for people with learning disabilities. TEC's social care programme aims to support the introduction and embedding of digital approaches and technology across social care and social work in Scotland. As a result, projects within the programme tend to focus on transforming systems within health and social care services, testing new digital technologies within these services, and upskilling staff with digital skills. This tends to be what is meant by the term digital transformation.

Given that people with learning disabilities are often viewed first and foremost as service users, and developments in these areas have been driven by support staff and carers, SCLD was keen to address this imbalance and use this funding to begin to understand what people with learning disabilities need and want when it comes to digital technology. It is only by doing this that we can understand if and how digital transformation can be transformative for people with learning disabilities.

Research aims and methods

The overarching aims of this research were to understand how people with learning disabilities were using digital technology currently, what they want and need from digital technology, what digital technology is out there to transform people's lives, and, if and how people are being supported to engage with it. The research was conducted using qualitative methods and taking a participatory action approach, comprising:

- Recruitment of a paid 'Digital Navigator Board,' including people with learning disabilities and their families to help steer and advise the project.
- Development and delivery of a co-research training course to allow Board members to undertake primary research with their peer networks.
- Semi-structured focus groups undertaken between Board members and their peer networks.
- Semi-structured focus groups undertaken within People First (Scotland) groups.
- An accessible self-complete survey made available for those who wished to take part in the research independently.

Digital Navigator Board

Between November and December 2022, SCLD recruited a Board for the project, comprising ten individuals with learning disabilities who live independently and advocate on their own behalf, and five individuals with learning disabilities whose participation in the project is enabled by the support and advocacy of a family

carer or support worker. Board members were recruited on the basis that they had some experience using digital technology and were able to offer their experience to develop a set of research questions, promote the project in their networks and help to direct the overall aims of the project. Board members were also offered the opportunity to undertake the role of co-researchers for the project.

Co-research training and implementation

Between December 2022 and January 2023 SCLD developed a co-research training programme for Board members who live independently and advocate on their own behalf. The training comprised a half day interactive workshop where Board members were introduced to different types of research, the ethics of research and how to run successful focus groups. A total of 11 members of the Board (including one individual whose participation was enabled by a family carer) undertook the research training. Four Board members went on to successfully arrange and facilitate focus groups with their peer networks, with support from the SCLD research team. One member of the Board was keen to arrange a focus group but was not able to due to circumstances outwith their control.

The co-research offer for Board members whose participation was enabled by the support of family carers and support workers was to tell their own story of how digital technology had impacted on their lives, using a mix of media including audio, video and photography. These stories were made into short animations, which are available [here](#).

Semi-structured focus groups and self-complete survey

The Board worked alongside the SCLD research team to finalise the question set for the focus groups, in line with their own experience and what they felt should be the priority for the research project. Four co-researcher led focus groups were undertaken with Board members' peer networks, including those in supported living, community organisations and an additional needs youth group. A further four focus groups were undertaken by People First (Scotland), including their National Group, their Hospital Advocacy project, National Women's Group and a local group, and fed into the project team at SCLD. A total of 98 participants were spoken to as part of the focus groups. The question set was adapted into an accessible self-complete survey and promoted through SCLD and the Board's networks. A further 16 responses were fed in this way. A total of 114 people fed their views into the project.

Analysis

SCLD undertook thematic analysis using the transcripts from the focus groups and open text from the surveys, to identify common themes.

Interpreting the findings

This project was not intended to produce an exhaustive exploration of the experience of every person with a learning disability in relation to digital inclusion and the use of digital technology. It is impossible within the parameters of such a project to do justice to each individual experience. It was also not intended to provide an exhaustive exploration of the many types of digital technologies and innovations that exist and could be utilised to transform the lives of people with learning disabilities. The digital landscape is continually changing. However, it aims instead to explore the common themes within people's experiences, of using digital technology, assuming the common issues affecting the participants are likely to be similar in the wider population, and to use those common themes to push for changes to policy and practice in digital health and social care and more generally.

What do we already know about digital technology use for people with learning disabilities?

Digital technology use – who, what and how?

The collection of robust data on the lives of people with learning disabilities is severely lacking in Scotland, and data on how people with learning disabilities engage with digital technology is no different. However, there are several reports and data that we can draw upon.

Official statistics show that disabled people are more than four times as likely to have never used the internet than non-disabled people (14.9% and 3.4% respectively) (Office for National Statistics 2021). A qualitative evaluation of the UK Government's Digital Lifeline programme suggests that as many as 35% of people with learning disabilities do not have digital skills for life, compared to 21% of the general population (Good Things Foundation 2022). A survey undertaken by SCLD in 2019 showed that only 33% of people with a learning disability had used social media in previous weeks compared to 61.5% of the general population (Scottish Household Survey 2019).[1]

> 35% of people with learning disabilities do not have digital skills for life.

A 2019 report released by Ofcom suggested that in terms of technology ownership, people were most likely to **own** a smartphone, closely followed by a computer of some form. The types of technology people with learning disabilities were most likely to **use** were the internet, and smartphones. Worryingly, nearly two in ten (18%) of those surveyed said their use of TVs or computers was limited or prevented, while around one in ten said the same was true for the internet, landline, smartphones or simple mobile phones (Ofcom 2019).

The same report suggested that the most common reason for the use of the internet by people with learning disabilities was communication, with 76% of internet users with a learning disability saying they used it for this reason. The second most common use was information gathering at 56%. The least common reason for people

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1 Bespoke analysis provided by Ipsos Mori

with learning disabilities using the internet was access to public services, at only 32% ([Ofcom 2019](#)).

It is important to note that the Ofcom report was undertaken before the Covid-19 pandemic. Research undertaken during the pandemic suggested that Zoom, email, tablets and WhatsApp were the most common forms of digital technology that people with learning disabilities were being supported to use, with the particular mix of technologies depending on what technology the supporter was familiar with and the person had access to ([Seale 2020](#)).

The Coronavirus and people with learning disabilities study asked several questions, which help us to understand how people with learning disabilities have been using technology since the beginning of the Covid-19 pandemic. It found that 88% of people who were advocating on their own behalf while participating in the study were able to utilise the internet at home, with the most common reasons being social media (60%), watching videos or streaming TV (58%) and being with family and friends online (53%) ([Hatton et al. 2023](#)). The same study found that smaller proportions of people with profound and multiple learning disabilities (PMLD), were generally reported to use the internet for all purposes compared to people who were advocating on their own behalf. While 63% of people with PMLD had access to the internet at home, the most common reasons for using the internet were watching videos (41%), streaming TV/films (37%), listening to music (34%) and being with friends or family online (30%) ([Hatton et al. 2023](#)).

Statistics on how people with learning disabilities are using specialist technologies are even harder to come by. Public Health Scotland produce annual statistics on technology enabled care (TEC) use – with TEC defined as the use of a community alarm system and/or a telecare package. The rate per 1000 in the population using TEC has remained relatively stable over the previous few years falling slightly from 23.6 in 2015/16 to 23.5 in 2021/22 (Public Health Scotland 2023). The same publication suggests that around half of those receiving social care across Scotland in 2021/22 were in receipt of a telecare service – this compares to less than a fifth of people receiving social care services who have a learning disability (Public Health Scotland 2023).[2]

While the uptake of TEC seems to have remained stable, the use of other technologies within health and social care has increased exponentially due to the pandemic. According to the Scottish Government's Digital health and Care directorate, since the beginning of the Covid-19 pandemic 1.4 online appointments have been undertaken across health, care, public, and third sectors services, and 30,000 patients have used remote monitoring for hypertension alone during the time of the Covid-19 pandemic (Digital Health and Care Scotland 2023).

A study into telecare stakeholder engagement found that of the 125 social care users consulted, around half used telecare (Fyfe 2023). The same study found that 58% of participants did not understand the term telecare. Additionally, 31% of people either disagreed or strongly disagreed that the application process for telecare was clear, and nearly 20% disagreed or strongly disagreed that information on telecare was available in various formats (Fyfe 2023). This illustrates a need for more readily available information on telecare, including accessible information for people with learning disabilities.

> While the uptake of TEC seems to have remained stable, the use of other technologies within health and social care has increased exponentially.

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2 Bespoke figures from the Source Social Care dataset provided by Public Health Scotland and analysed by SCLD. It is important to note these figures are an estimate, on the basis of the local authorities that submitted data. For further information please go to: Insights in social care technical document (publichealthscotland.scot)

Benefits of digital technology for people with learning disabilities

Although much focus in the literature is given to the digital exclusion faced by people with disabilities, digital technology brings many benefits, in particular promoting agency and independence, leading to more connected and enriched lives.

Even before the Covid-19 pandemic created conditions of necessity, studies have shown the benefits of being online. The internet is recognised as providing people with learning disabilities opportunities for personal development, activity and enjoyment, making and maintaining relationships, learning and employment (Chadwick, Chapman and Caton 2019).

During the Covid-19 pandemic, in attempt to combat digital exclusion, the UK Government funded tablets, data and digital skills training for 5,500 people with learning disabilities in England and Wales. Though it is important to consider the context of the pandemic, an evaluation of the project found that most people had improved their digital skills, felt less lonely and isolated, with improved health and well-being. People also reported feeling more independent and more motivated to go online (Mackey et al. 2022). This shows us that intervention combining the provision of digital technology with training and financial support can transform the quality of life for people with learning disabilities.

Digital technology can also promote social inclusion for people with learning disabilities. An Australian study found that during the Covid-19 pandemic, people with learning disabilities used mobile technology to keep in contact with the outside world in many ways. Examples of this include, online access to social work, shopping, support, meeting new people online, online banking, mental health support, work, and entertainment (Danker et al. 2022).

> " Digital technology can also promote social inclusion for people with learning disabilities. "

These findings are mirrored in other studies. A 2020 study looked at the impact of the Covid-19 pandemic on people with learning disabilities and the role that digital technology played in their lives during this time, speaking with self-advocates and supporters. The main reasons supporters gave for using technology with people with learning disabilities were, to contribute to good mental health or well-being, to combat loneliness, to overcome boredom, and to inform people about staying safe from Coronavirus. It was found that using technology at the time of the Covid-19 pandemic had a positive impact of mental health, well-being and created a sense of belonging and connectedness among people with learning disabilities. Additionally, the use of technology during the

pandemic has highlighted the technological capabilities of people with learning disabilities (Seale 2020).

Research looking specifically at the experience of people with PMLD using digital technology during the Covid-19 pandemic, highlights many benefits. People were able to use the internet to help maintain their relationships with their friends, family and community groups, with many able to continue accessing services they would have previously attended in person. For many people, digital participation was a new and positive addition to their life, with many able to access activities they could not before. Additionally, remote health appointments were often found to be more accessible than in-person health appointments. With additional support, people with PMLD were able to learn new skills using digital technology (Caton et al. 2022).

An under explored, but notable benefit of digital technology for people with learning disabilities is as a tool for education. American research that looked at the effects of using iPads to aid children with learning disabilities aged from 7–10 with their reading comprehension found that there were moderate improvements in reading for the participants (Alqahanti 2020).

While it is important not to overstate the advantages of digital technology for people with learning disabilities, it is clear there is huge potential for people to benefit across many different aspects of life.

Challenges, barriers, and digital exclusion

While there are benefits of digital technology as explored above, research has highlighted numerous barriers that exist for people with learning disabilities that result in digital exclusion. The internet and digital technology are not designed with accessibility in mind and are not accessible

for people who may need support to read and write or follow complex processes. Financial barriers, digital skills and attitudes of supporters, lack of support and training aimed at people with learning disabilities and constantly updating operating systems are just some of the barriers that people face (Chadwick, Chapman and Caton 2019, Shekhar 2019, Seale 2020).

Research looking at digital exclusion during the Covid-19 pandemic found that many of the barriers remained, despite government policy and strategy aimed at getting people access to technology to combat social isolation. A 2022 study found that many barriers were cost-related, as things like smartphones, computers and Wi-Fi were found to be prohibitively expensive. Some barriers were access related as many people had a poor internet connection or a lack of up-to-date technology. Some people also found accessing technology stressful and, as a result, refused to use it further, despite new offers of support. Some barriers were environment related, as many people lived in care homes which still did not provide access to technology. It was found that many staff members and support workers were unqualified to offer tech support. Some organisations had information security and safeguarding policies which prevented residents from using digital technology (Seale 2022).

> "Financial barriers, digital skills and attitudes of supporters and lack of support and training are just some of the barriers that people face."

These findings are supported by a study conducted on behalf of Lewisham Speaking Up. The report found many people still did not have access to devices, day services lacked hardware and expertise to support people, paid and unpaid carers did not have digital skills or training, and many organisations lacked the funding for hardware and software that would best accommodate people with learning disabilities (Ramsbottom 2021).

It is also important to consider the fact that people with PMLD face unique challenges and barriers to accessing and using digital technology. Research has shown that people with PMLD will always need to have additional support when using digital technology and highlights the fact that it is much more difficult in general for people to express their own choices and exercise control over when, where, and how they used digital technology in their lives (Caton et al. 2022).

Online safety and privacy

As well as the barriers explored above, worries around online safety and privacy are often cited by carers and supporters as a reason for limiting access to the internet and digital technology, as well as people with learning disabilities themselves. A qualitative study examined the experiences of people with learning disabilities when

it comes to online safety and risk. People had experience of having social media accounts hacked, receiving and sending viruses, online bullying and even being sent pornography (Chadwick 2022). It was clear that more support and training was needed to help people navigate online risk. Participants were most often aware of the risks of hacking, grooming and being contacted by strangers, but participants' awareness of cybercrime was dependent on whether they had been warned by carers and friends. Most participants wanted to develop their knowledge of online risks further. Some people responded to these risks by completely avoiding social media, whereas others were subject to gatekeeping and restrictions from family members due to financial concerns and worries about risks (Chadwick 2022).

An Australian study supports these findings. Participants expressed concerns about the dangers of using mobile technology, with some having been involved in what they called, online "drama." One participant said they were a victim of "trolling" in the past. Some reported being hacked and others were wary of using apps which tracked their locations. A third of the participants were careful with the personal information they shared. Participants also said they felt they needed to use passwords to protect and keep their information safe (Danker et al. 2022).

Support and training

The right support and training around being online and accessing digital technology are key enablers of digital inclusion for people with learning disabilities.

Indeed, a review of research into the digital inclusion and participation of people with learning disabilities during the Covid-19 pandemic highlighted technical support as a prerequisite for people with learning disabilities to benefit from online social participation and services, with a person's personal or paid support network the most likely to provide this (Chadwick et al. 2022). The same review found the support received to use digital technology could vary according to circumstances, with people living in supported accommodation and older people living on their own less likely to receive support. Whether this support was given depended on attitudes as much as digital competence among service providers (Chadwick et al. 2022).

An underexplored topic in the literature is the need for training for people with learning disabilities themselves. However, a study exploring the experience of one grassroots disability organisation during the pandemic found that by providing the training required for using online platforms, this allowed its members with learning disabilities to take on active leadership roles hosting online events, which also developed their confidence, independence, and wellbeing (Spassiani et al. 2021).

Specialist technology use, and use of technology to access health and social care

Much of the research literature is understandably focussed on digital exclusion, in the sense of access to the internet and digital devices that enable this, such as Wi-Fi, smartphones and personal computers. There is limited research that focuses on how people with learning disabilities are utilising digital technology; whether that is consumer technology, specialist technology or health and social care technology, to enhance their lives. This is reflected in a recent review of the Learning Disability tech landscape in England (Bloomfield and Villa 2021), which found significant underinvestment in learning disability specific technology. The review also highlighted that little was being done to understand what people with learning disabilities themselves want and need, with much development in this area being driven by support workers and family carers. Most of the literature that does exist is oriented toward technology enabled care (TEC), rather than wider innovations.

A 2016 report examined the potential benefits of different types of TEC for people accessing services, including older people and people with disabilities (Lawlor and Campbell 2016). The research found that smart home technology could encourage people to keep mentally and physically active and allowed people to remain in their own homes for longer. The research showed some evidence that people who utilise remote monitoring systems can feel more independent. There was more evidence that telecare – consisting of services such as medication prompts, remote care delivery, video consultations, and remote physiological monitoring – can help people manage chronic medical conditions and reduce overall levels of mortality (Lawlor and Campbell 2016).

An important use of technology, especially given the impact of the Covid-19 pandemic, is the use of remote support services. American research looked into the effects of remote support services, such as home-based smart technologies, and remote support staff, by people with learning disabilities (Tassé et al. 2020). Overall, participants in the study had a positive attitude to remote support services. Most said that this form of support gave them a greater feeling of choice and independence, with many people saying that they felt more able to perform tasks for themselves. Most people also said that they felt more privacy when using remote support services than they did with exclusively in person support (Tassé et al. 2020).

> " Overall, participants in the study had a positive attitude to remote support services. "

Smart-speaker technology with virtual assistants have become widespread over the last few years, and understandably this has been the focus of several studies. Research shows clear benefits from the use of these devices, with most people who have used them gaining more independence and feeling a sense of empowerment (Smith et al. 2020). Interestingly, 80% of participants in this study felt they were better able to do things themselves because of the device use. However, only 27% of staff reported that participants were better able to do things themselves. This indicates a clear gap between people with learning disabilities' perception of themselves and staff's perception of them. The same study suggested the use of these devices supported improvements to people's speech and communication (Smith et al. 2021).

A 2018 report emphasised that significant investment in technology will be needed in order for care settings to effectively utilise TEC solutions, including basic Wi-Fi access, accessible tablets, individual mobile phones, and technologically literate staff before they could even begin to consider introducing more advanced forms (Chambers and Schmid 2018). Despite significant investment through the Connecting Scotland programme, this remains the case in Scotland today. Though not looking at technology enabled care specifically for people with learning disabilities, research by the Fraser of Allander Institute (2023) found that many from across the Scottish social care workforce felt they lacked the digital skills and training to realise the full potential of innovations in TEC. Staff felt that for services to utilise the technology effectively, they would not only have to be able to use it themselves, but also be able to train others on how to use it. Worries were also expressed regarding the fact that TEC is not necessarily accessible for service users, as well as potential privacy concerns where people were not able to consent to monitoring devices (Fraser of Allander 2023).

What did people tell us about their experiences using digital technology?

As discussed above, the Digital Navigator Board worked alongside the SCLD research team to finalise the question set for the focus groups, in line with their own experiences, and what they felt should be the priority for the research project. The question set was also adapted into an accessible self-complete survey.

Exhaustive descriptions of digital technologies were not provided in the focus groups, or the survey. Though a question about specialist technology was included in the research, specialist technology was not defined, other than to differentiate it from non-adapted consumer technology. Further, people with learning disabilities are not a homogenous group. Each person is unique, with different needs and living within their own set of circumstances.

Because of these factors, it is not possible to understand the full extent of how digital technology is being used by people with learning disabilities. Despite this, the surveys and focus groups did serve to highlight several common themes, which help us understand the main experiences and challenges faced by people with learning disabilities when it comes to accessing and using digital technologies. These themes are explored in this section.

Increasing consumer technology use since Covid-19

The Covid-19 pandemic was undoubtedly an extraordinarily terrible experience for many people with learning disabilities and their families, the impact of which is still being felt. However, lockdown created conditions of necessity in which many services had to move online. A perhaps unforeseen consequence was the fact that many people with learning disabilities were supported to get online and to use digital technologies, with the aid of the Connecting Scotland programme (Connecting Scotland 2020). Many participants in the focus groups acknowledged an increase in technology use during the pandemic, particularly for communication and staying connected with others.

"I have become much more confident using tech because of the pandemic, we were all practising together."

(Focus group participant, person with a learning disability)

"Since the pandemic I have been using technology to stay in contact, it has helped me. Before Covid-19, many people didn't have access to technology but now we have more access to tablets and learning new skills."

(Focus group participant, person with a learning disability)

Participants across all focus groups and surveys mentioned using various digital devices, including smartphones, tablets, laptops, and smart home devices. Commonly used apps and platforms included Facebook, Messenger, WhatsApp, Zoom, Teams, Alexa, Google and various entertainment and gaming apps.

"I use Facebook and YouTube, Netflix and stuff like that. I also use Amazon Music on my Smart Speaker Alexa as well."

(Focus group participant, person with a learning disability)

"I use my watch for reminders, so like timers for cooking or alarms if I have an event coming up because it's on my wrist it is more likely to be with me. I play games on my phone as well and I listen to music."

(Focus group participant, person with a learning disability)

"I use social media. I go on Facebook and use it for photographs."

(Focus group participant, person with a learning disability)

Though some people said they were happy using Teams, feedback from the focus groups supported anecdotal evidence that Zoom tended to be the preferred video-calling technology.

"A discussion took place about video calling apps and everyone in the group said they prefer Zoom to Microsoft Teams. In general, it was felt that Zoom has a more straightforward layout, is easier to navigate and feels more informal."

(Feedback from People First focus group session)

Theme 2:

Positive impact of digital technology

Participants across all the focus groups and the survey highlighted the many benefits of digital technology, including improved communication, staying connected with friends and family, as well as accessing information and entertainment.

"I find them useful to live my life, they are helpful tools. I use my phone to get me up in the morning. I use my iPad for group meetings and social meetings online."

(Focus group participant, person with a learning disability)

"It's changed my life. It's improved my quality of life. I can stay in touch with family and friends. It's good to keep in touch with friends that you've not seen."

(Focus group participant, person with a learning disability)

"It allows my daughter to actively engage with the world around her. It supports her to make choices and advances her learning. It builds her confidence. It allows her to communicate more effectively. It gives her more choice and control over her life. It allows her to communicate more detail; she can play games; learn; or passively watch T.V."

(Survey participant, parent/carer of a person with a learning disability)

Several participants highlighted that digital technology has allowed them to be more independent.

"It gives me independence and things to do with my spare time, so I don't get bored. It lets me have manageable contact with people I love. It lets me pursue my interests."

(Survey respondent, parent/carer of a person with a learning disability)

"It has allowed me to be more independent because I can now write things myself. Otherwise, I think I would be quite stuck because I would need to get help from people more."

(Focus group participant, person with a learning disability)

"Voice notes are great for me because it means I don't have to read or write."
(Survey respondent parent/carer of a person with a learning disability)

Some participants also highlighted that technology was beneficial for enhancing personal safety through tracking and assistive apps, though this needs to be balanced with choice around when any tracking apps are enabled.

"I use the Life360 app with my parents, which is a type of tracking app. I was away in an unfamiliar city and my dad saw I wasn't in the hotel and was able to message me and ask if I was lost. This makes me feel safe if I'm somewhere new, because I'm bad with directions, the fact my dad can find out I'm going the wrong way. If I'm somewhere I know, I don't really like it much. So, I only use it if I'm travelling."
(Focus group participant, person with a learning disability)

Voice-controlled devices like Amazon Alexa were particularly beneficial for individuals who might find it difficult to use touch screens.

"I support someone who struggles with touch screens. Pre-pandemic they had a phone with buttons, but it broke, and the only option was a touch screen. They went into a trial to use an Alexa – the person is muffled when speaking but manages to communicate with Alexa. They now have lights connected to it, alarms, and will sets timers on it. Sometimes just to test staff to see if they are paying attention! They can ask for football scores. It has opened their world up."
(Focus group participant, support worker)

Challenges, barriers and fears over online safety

Despite many clear benefits from using digital technology, participants told us of challenges and barriers they faced.

Lots of people told us about difficulties they had with specific apps and web platforms, which are not designed with anyone with additional support needs in mind. These included apps that had been developed during the Covid-19 pandemic to support the vaccine roll out, or those that had been scaled up during the pandemic, such as NHS Near Me.

"I've used the Covid-19 app. It is very complicated to set up as you have to know a lot of your details. The current online system for booking the vaccines is really hard."

(Focus group participant, person with a learning disability)

"NHS Near Me is very clunky. It just doesn't feel very smooth."

(Survey respondent, parent/carer of a person with a learning disability)

"NHS 24 should have easy read information you can click on if needed."

(Survey respondent, person with a learning disability)

While people understood why passwords and other security measures were important, at times these caused difficulties for people.

"It is hard to remember passwords, and bank details. Some people do need help to log in. I can do it myself but know I can ask staff or my dad."

(Focus group participant, person with a learning disability)

"Extra security presents another barrier. Before you would use a password and now you need two factor authentication, and that for some people can be a barrier because there are even more things to remember!"

(Focus group participant, college lecturer)

Connectivity issues have long been a barrier for many people accessing the internet. The focus groups highlighted that this is also the case for people with learning disabilities and can be exacerbated by limited phone contract options.

"The Wi-Fi is really bad where I stay, and I have to use my data to get online."

(Focus group participant, person with a learning disability)

"When my 4G runs out I didn't have internet, it's a lot of money to keep topping up my phone. I couldn't get unlimited data."

(Focus group participant, person with a learning disability)

The focus groups also highlighted frustrations using digital technologies when they did not work as expected, because people are not always equipped with the right skills and confidence to overcome these challenges.

"I can't read emails. And some emails on the computer it won't read out. Sometimes you have to download an app onto the laptop to read it, and get it to work, and then it might not work, and you have to redownload it. There is a lot of skill involved in that."

(Focus group participant, person with a learning disability)

"Sometimes the technology does not work or plays up and you end up getting chucked out of a call which is frustrating."

(Focus group participant, person with a learning disability)

The financial implications of using technology were a concern for people, including the cost of internet access and the cost of different technologies. This barrier is increasingly concerning given the rising cost of living.

"The main barriers are costs and access to buying technology and internet. Some technology doesn't last long, my mobile battery doesn't hold a charge for very long."

(Focus group participant, person with a learning disability)

"The main barrier for assistive technology is that you have to pay for it."

(Focus group participant, person with a learning disability)

Across all the focus groups and surveys, concerns about online safety were a common theme. These worries were so pervasive that some people avoided doing certain things online. There were examples where people were not allowed online, either by family or supporters, to keep them safe from these risks.

"I don't like to do shopping or personal things online. Giving out bank details and things. You never know what scammers might be out there."

(Focus group participant, person with a learning disability)

"My friend got us into trouble because someone online posed as our respite worker, and she shared my details and her own bank details. They stole money from her. Social work and the police got involved and phoned my mum to notify her that it was organised fraud targeting people with learning disabilities. It was very stressful, and I didn't understand what was happening."

(Survey respondent, parent/carer of a person with learning disabilities)

"I'm not allowed on Facebook."

(Focus group participant, person with a learning disability)

Some participants highlighted that by virtue of the setting in which they lived, access restrictions are a barrier.

"Access to internet and social media is very restricted in a hospital setting. Support and permission are needed to connect or even use devices, as they are often locked away after use."

Another worry about being online that was highlighted in the focus groups was the potential for cyberbullying, with some people opting to avoid certain apps and platforms rather than put themselves at risk. Again, some people told us that their parents or supporters didn't allow them on certain apps because of this.

"I've been working with a couple of people who have been bullied and have also had a lot of inappropriate material coming through from social media. So, it's good [being online] but not without its risks."

(Focus group participant, youth group leader)

"I avoid Snapchat and TikTok. I don't use Facebook much. Just to message people that I already know in person. This is to avoid the bullying side of it because I've been on the other side of it both online and offline."

(Focus group participant, person with a learning disability)

Theme 4:

Facilitators to accessing digital technology, and the role of staff and support

As well as the challenges, people told us about some of the things that made it easier for them to access digital technology. One of the biggest factors is having the skills and confidence to get online and use technology, and knowing how to access the accessibility software that is often built in. Sometimes that skill and confidence came from practice, but others highlighted that their skill and confidence came from being shown or having training in how to use technology.

"There are a lot of in-built things that make your computer and things easier to use. I went to college and got told about the process of it all. You can talk to your computer, and it can type for you. But it doesn't always understand your accent."

(Focus group participant, person with a learning disability)

"At the start I got a bit of help from staff at my group on how to do it. Another member of the group sent a really good video from YouTube on how to use Zoom. Lots of members fed back and said it was useful."

(Focus group participant, person with a learning disability)

A recurring theme throughout the focus groups and survey was the importance of supporters – whether family members or paid support staff – having the time, digital skills and confidence to help people to access and use digital technology.

"Time is my biggest barrier. I am reasonably techy but tech changes so often requiring lots of time to invest in learning new skills as a parent carer I need to be able to learn something first to then show my child. Those supporting my child don't always have the right level of knowledge and or confidence to use tech."

(Survey respondent, parent/carer of a person with a learning disability)

Staff members taking part in the focus groups also acknowledged the need for improved digital skills to effectively assist individuals in using technology.

"The issue of staff and technology is a big issue, and a big barrier to the people we support using technology. It's difficult for staff because it's not a core part of their work. We as an organisation and the sector more generally really need to think about it."

(Focus group participant, support worker)

Despite more people with learning disabilities getting online throughout Covid-19 and since, there are still many who are not able to go online because they have not had the right support around them.

"Some people at our group still don't use Zoom or technology because they don't know how to, or because they live on their own and don't have anybody to support them. Our organisation had the chance to give out free iPads to members that don't have them so they can keep in contact, but there were two or three members who didn't want one because they wouldn't have the support or guidance to show them how to work it."

(Focus group participant, person with a learning disability)
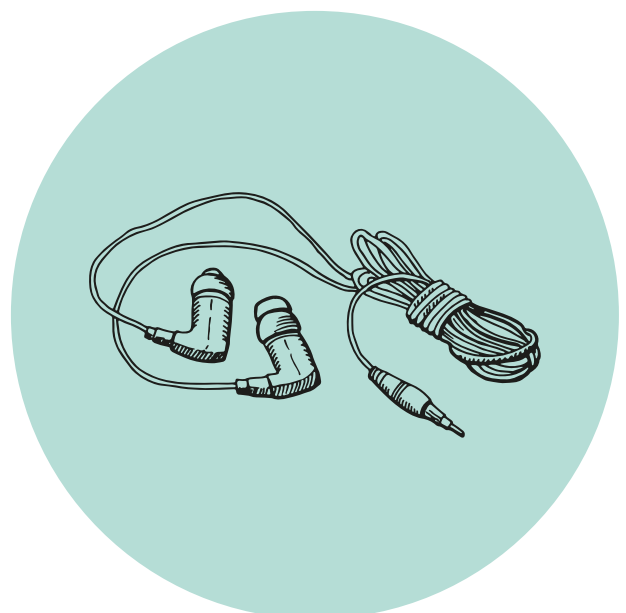
Limited use of specialist technologies

As outlined above, during the focus groups, specialist technology was not defined, other than to differentiate it from non-adapted consumer technology.

It is important to acknowledge that for many people with learning disabilities specialist technology is a synonym for technology enabled care (TEC), and TEC is often viewed as diminishing the care and support people receive, in large part due to often being introduced in the context of cost saving, rather than enabling independence.

Interestingly, most people that we spoke with, said they had not used specialist technology. Those who had, tended to be using some form of telecare service.

"I use my alarm on my wrist in case I fall when I'm in the house – it's really handy to have."

(Focus group participant, person with a learning disability)

"I have an emergency alarm button in case I fall and hurt myself. This only works when you are inside the house."

(Focus group participant, person with a learning disability)

Participants expressed worries over the use of specialist technologies, in particular the impact on privacy and financial implications.

"We did some work with a company called CareZapp. We were using a sensor. We learned that someone was spending time in her chair that we hadn't known before. This allowed us to make adaptations, which had limited success, and it was quite intrusive. We and the Care Inspectorate weren't sure about the benefit being worth the intrusion."

(Focus group participant, support worker)

"We've had some successes [with specialist technologies], but for the bespoke systems the costs were significant, around £150 per month, which is a huge amount. If someone had less support as a result it can offset those costs, but we've never managed to do this in reality."

(Focus group participant, support worker)

"When you say adaptive technology is for someone with a disability it's like a wedding – all of a sudden it's three times the price."

(Survey participant, parent/carer of a person with a learning disability)

One of the focus groups also highlighted that consumer technology was being used instead of specialist technology, due to financial issues.

"A person we support goes out a lot. Their family were worried they weren't coming home to eat. The person reported problems from neighbours knocking their door at all hours. So, their family set up a Ring doorbell so that they can see if someone comes to the door they can go and help. And they can monitor when the person comes in. This gives them peace of mind. They have a guardianship order, so are allowed to do this. They'd looked a more specific systems, but the Ring doorbell was cheaper."

(Focus group participant, support worker)

A few participants specifically mentioned that they had been supported by PAMIS to create a Digital Passport alongside their child with PMLD, which went some way to address communication challenges facing people who struggle to be understood by those who are unfamiliar with them. This had been particularly helpful in high stress situations such as unplanned hospital admissions.

People also spoke about using assistive technologies, such as screen readers and speech to text software. However, those creating websites and other apps need to design these to be compatible with such software, or their usefulness is limited.

"I use screen reading software, but organisations sometimes just use photos on website or apps to convey information rather than writing it out, and screen reading software is not very good at reading images and photos out so I end up missing out on information."

(Focus group participant, person with a learning disability)

Discussion

The findings from the focus groups and surveys provide an understanding of the experiences of people with learning disabilities when it comes to the use of digital technology. The Covid-19 pandemic brought about a notable increase in technology use, driven by the necessity of health, social care and community services moving to a model of online delivery.

> The Covid-19 pandemic brought about a notable increase in technology use.

Participants reported enhanced confidence and skills, particularly in the use of communication platforms like Zoom, and social media such as Facebook and WhatsApp. Various digital devices and applications were embraced, with voice-controlled devices offering useful benefits for some.
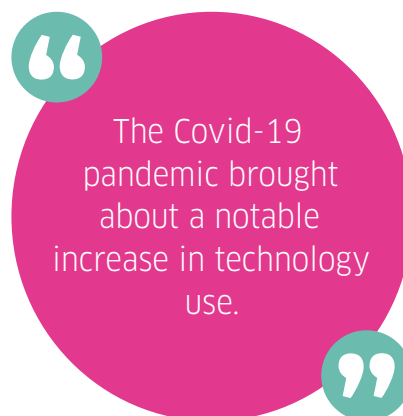
The positive impact of digital technology was evident in improved communication, connection with friends and family, and increased independence. Participants highlighted the transformative effect on quality of life, confidence, and choice. Digital tools, from reminders to assistive apps, contributed to personal safety, independence and autonomy.

However, challenges and barriers emerged alongside these benefits, many of which are long-standing issues. Participants faced difficulties with app complexity, security measures, connectivity, and affordability. Frustrations arose when technology malfunctioned, and concerns about online safety, cyberbullying, and potential scams were widespread. The financial implications of technology, including costs of internet access and devices, posed barriers for many.

Despite these challenges, facilitators of technology use were identified. Skills and confidence played a pivotal role, often acquired through training and practice. The role of supporters, both family and staff, was paramount in assisting individuals to navigate digital spaces effectively. The need for improved digital skills among supporters emerged as a recurring theme.

Few participants had experience of using specialist technology, with those who did mainly utilising relatively old-fashioned telecare services. People using Smart Speakers to set reminders hints at what is possible from consumer technology in terms of enabling more independence. However, support staff raised numerous issues around cost, privacy issues and general lack of understanding on their own part in relation to investing in specialist technologies to enable independence for people with learning disabilities.

It is clear that the experiences of people with intellectual disabilities in using digital technology are multifaceted. The pandemic's influence accelerated technology adoption across all aspects of life, fostering positive outcomes in communication, independence, and engagement. Nonetheless, challenges such as app complexity, security, connectivity, and affordability persist. Effective assistance from supporters emerged as a key determinant of successful technology utilisation.

Moving forward, addressing these challenges and enhancing digital accessibility alongside innovations in health and care technology will be crucial in ensuring that the potential benefits of digital technology are fully realised for people with learning disabilities in Scotland.

Recommendations for moving forward

The nature of this project has resulted in covering, and uncovering, a wide range of issues and innovations in the use of digital technology for people with learning disabilities. This project has come across many excellent examples of how digital inclusion can be done, and how both digital inclusion and innovations in technology across different sectors can improve people's lives. Our Annex below highlights some of these examples.

None of them alone will solve the issues uncovered within the research, and because of this, it is difficult to put forward a set of recommendations that will truly lead to transformative change for people with learning disabilities in Scotland.

However, building on everything that we already know about the lives of people with learning disabilities, what we have learned as part of this project, and taking account of the Scottish Government's priorities set out in the Digital Health and Care Strategy, SCLD believes there are a number of recommendations that will help bolster digital inclusion and promote digital solutions for people with learning disabilities in the short to medium term. It is hoped that these will lay the foundations for transformational change in the longer term.

The Scottish Government should provide funding for learning disability digital inclusion coordinators across Scotland

Only by achieving digital inclusion will we ensure that digital transformation is truly transformative for people with learning disabilities in health and social care and beyond. There are many excellent digital inclusion projects taking place across Scotland. However, few are specific to people with learning disabilities, with most either generic, or taking place within specific social care settings.

> "There are many excellent digital inclusion projects taking place across Scotland."

The Scottish Government should fund learning disability digital inclusion coordinators across Scotland. Their role will be to bring together networks dedicated to finding person-centred solutions to digital exclusion and promoting digital technology and participation for people with learning disabilities. As well as pushing for digital inclusion within services for people with learning disabilities, they would work with existing digital inclusion services to ensure their offer is open and accessible to people with learning disabilities.

As many people with learning disabilities are not in touch with traditional health and social care services, these networks should include collective and self-advocacy groups, community organisations, families, day service providers, support organisations, health and social care professionals, and people with learning disabilities themselves, to collect and share examples of success and best practice around digital inclusion, discuss common challenges, opportunities for funding, training and partnership working.

Development of such a model should consider the successes of similar models in Leeds and Coventry, as well as learning from the TEC Programme's current digital inclusion in mental health and housing workstream.

Recommendation 2:

The Scottish Government should provide funding for a learning disability lived experience board focused on digital health and social care services and technologies

The Scottish Government's TEC programme acknowledges five pillars of digital inclusion; motivation, devices, connectivity, skills and confidence, and, inclusive design, with each pillar building on the next (Slater and French 2023). SCLD believes that inclusive design is the foundation for the other pillars, and is often missed, either due to cost, or the lack of time between a policy commitment being made, and its implementation.

However, if the Scottish Government is to realise its ambition to improve the care and wellbeing of all in Scotland, by making the best use of digital technologies in the design and delivery of services, then inclusive design must be considered from the beginning. To do otherwise is to surely perpetuate the inequalities that already exist across society, and for people with learning disabilities in particular.

To achieve this, the Scottish Government must value and include the voices of people with learning disabilities across the Digital Health and Social Care strategy delivery plan. This can be done by funding a lived experience board to provide expertise at every stage of the design and delivery of digital services and solutions that will impact on them. Importantly, this must include as paid advisers and accessibility testers. Any equality impacts uncovered during these processes must be mitigated at the design-stage rather than simply referred to within an equality impact assessment.

> " The Scottish Government must value and include the voices of people with learning disabilities. "

This is particularly important in relation to the Digital Health and Social Care directorate's strategic priorities, including the Digital Front Door and the creation of an integrated health and social care record.

If a lived experience board is not the approach chosen, it is vital that an alternative route, which ensures people are meaningfully included as advisers and accessibility testers is found.
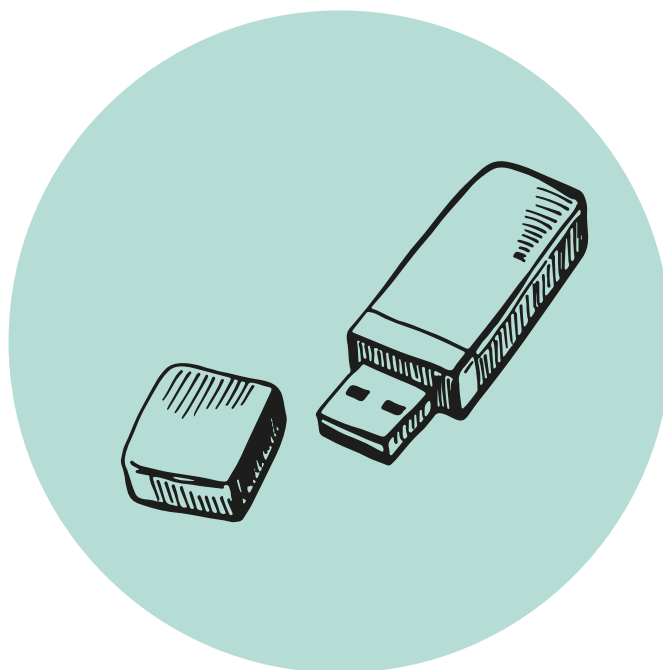
Recommendation 3:

The Scottish Government should support a co-produced learning disability pathfinder project utilising personal data stores to empower people to interact with health and social care services

While poor communication is the fault of systems, not of individuals, where systems fail to recognise people's needs, this leads to poor outcomes. This is particularly important in health and social care.

There are many great examples of initiatives, which allow people with learning disabilities to store important information about themselves that can be shared with others when needed. The PAMIS digital passport is one such initiative that came up in the exploratory work for this research and is an exemplar of person-centred care and support. If we are to improve health and social care outcomes for people with learning disabilities, then the system needs to be able to engage with and understand their needs, in times of crisis as well as planned interventions.

The Scottish Government should support a co-produced pathfinder project, utilising personal data stores, where people are able to add their health, wellbeing, communication and support information to this data store, and share this with others, including health and social care services.

To get this right, this pathfinder must include experts by experience, organisations with experience of co-producing such initiatives with people with learning disabilities and be supported by an organisation with expertise in health and social care innovation. All must be equal partners in the project.

The Scottish Government, Public Health Scotland and NHS Boards must ensure a joint approach, with adequate resources, to learning disability data improvement

Though this project did not actively set out to scrutinise the data available in relation to people with learning disabilities across the digital health and social care landscape, it has highlighted yet again the inadequacy of the data captured on the lives of people with learning disabilities. It would be remiss not to acknowledge this.

Considerable health and social care equalities data improvement work has been taking place across Scotland, recognising the difficulties faced identifying people for vaccinations, as well as understanding the impacts of Covid-19 on different population groups. In relation to people with learning disabilities specifically, work is taking place within health boards to ensure that all people with learning disabilities are identified and invited for newly implemented annual health checks.

It is imperative that this data improvement work does not happen in silos. The Scottish Government, Public Health Scotland and Health Boards must take a coordinated approach to this work, including pooling resources to ensure significant investment in local data systems, to lay the groundwork for success across several of the Scottish Government's strategic priorities in health and social care. Putting in place a reporting structure around this data improvement work would be useful to ensure accountability.

> "It is imperative that this data improvement work does not happen in silos."

As well as the obvious benefits in terms of understanding the lives of people with learning disabilities and supporting fair and equitable health and social care outcomes, in the longer term, data improvements would support the ability of Health and Social Care Partnerships to understand what specialist technologies are being used to support people with learning disabilities, and ultimately fund and provide technologies to those who do not have them but could benefit from them.

Concluding Comments

As discussed above, there are clear measures, aligned with the Digital Health and Social Care delivery plan, that can be taken in the short term to improve digital inclusion and digital solutions for people with learning disabilities within health and social care, and beyond.

However, for any change to be truly transformative, wholesale cultural change is needed. The health and social care sector, and society in general, need to see people with learning disabilities as more than service users. We need to spark a cultural change whereby stakeholders are committed to encourage people with learning disabilities to explore and independently use technology, with appropriate measures in place to ensure people can make informed choices about its use.

"For any change to be truly transformative, wholesale cultural change is needed."

Only in so doing will people with learning disabilities be able to see the transformative benefits technology can bring in terms of more independence, choice, and control.

As the transition towards a digital society continues apace, now is the time to make sure that no one, including people with learning disabilities, is left behind.

Annex: Spotlight projects and technologies

By virtue of this project, SCLD has come across many technologies and projects that have been beneficial to people with learning disabilities in relation to digital inclusion and digital transformation; or have the potential to be. SCLD felt it was important to highlight some of these, though this is not intended to be an exhaustive list of all the technologies and projects that are available.

A number of other organisations and projects are highlighted in our sister paper, written by Emma Pauley Co-production, exploring what digital technology is being used by the third sector to support people with learning disabilities. This paper is available here.

Projects enabling digital inclusion for people with learning disabilities

Autism and Learning Disability Digital Inclusion Network (ALaDDIN)

ALaDDIN was created by the 100% Digital Leeds programme at Leeds City Council in response to the changes and challenges that organisations faced in adapting their delivery of services because of Covid-19.

100% Digital Leeds is working with organisational partners, people with learning disabilities and autistic people to build a citywide infrastructure that helps provide solutions to these barriers, and to create an inclusive, person-centred model of digital activity and participation. This includes developing training opportunities for individuals, family members, carers, support workers, staff and volunteers at community organisations, as well as sharing best practice, common challenges, opportunities for funding and partnership working.

ALaDDIN has a dedicated Autism and Learning Disability Digital Inclusion Coordinator. The role has been funded by the NHS Leeds Clinical Commissioning Group. It is matrix managed by Pyramid of Arts, a community organisation working with people with learning disabilities and autistic people, and 100% Digital Leeds.

Current priority workstreams include:

- Supporting organisations to use accessible digital technologies to improve the health and wellbeing of autistic people and people with learning disabilities.
- Supporting organisations to use digital technologies to move people with learning disabilities and autistic people closer to employment.
- Using digital technologies to enable people in supported living environments and residential settings to learn new skills, access social activities and increase their independence.

[Autism and Learning Disability Digital Inclusion Network – 100% Digital Leeds (digitalinclusionleeds.com)](#)

Carr Gomm Digital Inclusion Research Project

Carr Gomm is a leading social care and community development charity, supporting over 3,000 people every day across Scotland to live their lives safely and well. People Carr Gomm support are at risk of digital exclusion for a number of reasons, including the cost of connectivity, accessibility of devices, and a lack of opportunity to develop digital skills and confidence. In 2021, Carr Gomm launched the Digital Inclusion Research Project (DIRP) to learn more about the digital needs of people we support – and staff – to ensure everyone has the choice and opportunity to get online.

Using an action research approach, DIRP works in collaboration with frontline services to design and deliver their own bespoke approaches to providing person-centred digital inclusion support. Each team is supported by Digital Ambassadors; frontline support practitioners with a passion and motivation to share their digital skills with people Carr Gomm support and their wider teams.

To date, DIRP has collaborated with 15 Carr Gomm services to explore digital in a variety of different ways, including:

- Supporting people to strengthen their essential digital skills as a means of having more choice and control in daily life via online shopping/banking, continuing education, and keeping connected with their community.
- Establishing device and connectivity banks across remote, rural areas to support older people to get online.
- Designing accessible, enhanced support plans to ensure people Carr Gomm support have an active voice in their support planning.

Learning from the past two years of DIRP is helping to inform the foundation of Carr Gomm's new project, **Connected Lives**, funded via the Digital Pioneers Mental Health Fund. This project will involve working alongside people Carr Gomm support

and frontline staff in their Glasgow Integrated services to develop a safe, online peer network to support health and wellbeing. Learning from DIRP is also actively shaping the new digital skills training offer for frontline staff; ensuring all support practitioners feel comfortable in their own digital skills and are confident supporting people to get online.

Digital – Carr Gomm

Get2Gether's Digital Ambassador

Get2gether, is a third sector organisation who believe that everyone has the right to love and friendship. They also believe that people meeting each other should be easy, fun and accessible.

They arrange social activities for people with disabilities in safe and friendly places in Edinburgh and the Lothians.

In the wake of the Covid-19 pandemic, Get2gether appointed a member to be their digital ambassador. This role includes helping other members of Get2gether connect online with their friends and to make new ones. The digital ambassador also helps members improve their online skills, through video tutorials and skill shares.

Our Ambassadors – get2gether

Neighbourhood Networks and Mhor Collective Digital Champion training

Neighbourhood Networks is a social inclusion organisation supporting vulnerable adults, many with learning disabilities, physical disabilities and mental health issues to live an active, healthy life, safely, within their own homes and fully involved within local communities.

Mhor Collective is a community interest company dedicated to addressing digital inequality.

Mhor Collective was tasked by SCVO to undertake Digital Champion training with frontline staff from Neighbourhood Networks. Neighbourhood Networks invited their wider membership to the training. Mhor Collective immediately realised they would need to adapt their training to suit the members, so they did a piece of work with the members and asked them what they wanted to do. The members explained that they wanted to explore the fun stuff around digital, but that their

loved ones were so concerned about risk that they did not want people engaging in the digital space at all.

Mhor Collective and Neighbourhood Networks then ran a session for parents and carers where they were given a safe space to discuss what they were worried about and were provided with advice for mitigating risk. The sessions were well received by parents.

By being flexible, Mhor Collective kickstarted a digital champion revolution at Neighbourhood Networks, with everyone across the organisation, members and staff alike, working collectively to make sure that everyone can access the help they need to access the opportunities of the internet, which has led to outstanding services online, for everyone.

Home – Mhor Collective

Home – Neighbourhood Networks

Lead Scotland

Lead Scotland is a national charity supporting disabled people and carers by providing personalised learning, befriending, advice and information services.

Lead Scotland can help people improve their confidence to use the internet safely. From blog posts and webinars to 'Thinking Digitally' courses, there are resources for everyone. Through 'Thinking Digitally', Lead Scotland offer a guided, online, group learning environment with one-to-one support so that partner organisations are enabled to meet their digital needs.

LEAD Scotland – Linking Education and Disability » Specialist in linking education and disability

AbilityNet

AbilityNet is a UK-based charity with a vision of a digital world accessible to all.

They have been helping older people and disabled people of any age with their technology for 25 years. They have a network of more than 350 tech volunteers who can visit someone in their home or help over the phone.

They have a wealth of free information and resources that provide expert information about disability and technology and host a variety of webinars.

About AbilityNet | AbilityNet

Health and social care focused technologies and projects

PAMIS Digital Passport

PAMIS Digital Passports are visually engaging, multimedia e-books which are stored and used on tablet devices. They help people to communicate with those around them. For people who have complex health or social needs, the multimedia approach supports a variety of uses including:

- Social, emotional and physical care.
- Communication of choices and ideas.
- Support for sports and leisure activities.
- Supporting independence and abilities.
- Supporting person led care.

PAMIS Digital Passports are one of the resources that people who have profound and multiple learning disabilities and their family carers have helped to develop. The Passport addresses some of the communication challenges facing people who struggle to be understood by those who are unfamiliar with them. They are being used to support people of all ages at home, in education, and within health and social care settings.

PAMIS Digital Passports | PAMIS

ADAM – About Digital and Me

Developed by Alzheimer Scotland, ADAM is a new platform which helps people to find the right pieces of technology at the right time. Families and carers told Alzheimer Scotland that they would like to try using digital products and services to look after their health and wellbeing but were worried about making the wrong choices. ADAM is intended to make this easier.

ADAM uses artificial intelligence to ask some questions about the things that are important to people, and to make recommendations about digital products which they might find useful.

ADAM will outline why they have been recommended and give some insight into how easy they are to set up and use, and where they can be bought.

Adam (meetadam.co.uk)

ALISS – A Local Information System for Scotland

ALISS is a national digital programme, run by the ALLIANCE, which enables people and professionals to find and share information on resources, services, groups, and support in their local communities and online.

ALISS can help you find information about resources like:

- Services that provide support for managing long term conditions.
- Groups that support social and community connection.
- Activities that offer opportunities for getting more active and for getting outdoors.
- Practical, legal, and financial support.
- Digital technology that can support health and social care.

ALISS' aim is to ensure that everyone in Scotland has the right information, at the right time, about resources that are available to help them live well and stay connected to their community.

My Scottish Community is a version of ALISS that is available on Amazon's Alexa and allows people to search for information on resources, groups, and support in their local communities and online by voice and audio alone. My Scottish Community is what's known as an Alexa Skill. This sits within your online Amazon account and, once enabled, you can use it across any Amazon Alexa devices or within the Alexa app when you have logged into your Alexa account. The skill can be downloaded on any Alexa device or on the Alexa app on a smartphone.

ALISS – A Local Information System for Scotland | ALISS

Amazon.co.uk: My Scottish Community: search ALISS for support: Alexa Skills

SOL Connect

SOL Connect are technology enabled care specialists based in central Scotland. They offer advanced remote support through the very latest in technology, nationwide. They believe the future of social care lies in a partnership between person-centred, one-to-one support and a creative and bespoke technology enabled care package.

SOL Connect work in partnership with the individual to find out what they want their support to look like and tailor solutions to meet their requirements. They have a team of experienced practitioners available 24 hours a day, 7 days a week to offer around the clock remote support.

SOL Connect aims to:

- Promote on-going independence.
- Increase social inclusion and promote personal well-being.
- Make things easy to use with the aid of technology.

About SOL Connect | SOL Connect (sol-connect.org)

Other applications and projects

Human Rights Town

The Human Rights Town app allows people with learning disabilities to learn about their rights in a gamified app.

The development of the app was led by a group of people with learning disabilities who worked with SCLD and digital design company, Publishing Bureau, to create the finished product, which has the potential to be an effective tool for self-empowerment.

The app invites users to travel around a virtual Human Rights Town where they encounter different scenarios at each location, such as using public transport or working at the supermarket. Through practical examples Human Rights Town introduces users to each of their human rights, under the UNCRPD and asks them to choose whether they believe their rights are being respected or not in each scenario. Users have the option of further explanation at each location. Each scenario has been voiced over by a person with a learning disability who has helped to develop the app.

Human Rights Town – the app! – SCLD

Compass

Compass is a new online digital application from ARC Scotland to help make the transition to adulthood smoother for young people with additional support needs of all kinds. Working hand-in-hand with young people, parents and carers, and professionals, ARC has created three separate versions so everyone can understand the transitions process better and find useful information at the right time.

The tool supports young people to explore what matters to them and share their thoughts with people they trust. It gives parents and carers a transitions timeline that shows where they are in the process and points them to key actions at each stage. The professional version has guidance on the statutory duties that apply to transitions and clarifies responsibilities. All three are tailored to the individual, link to the best sources of information currently available, and are specific to Scotland.

Compass also collects completely anonymised feedback about experiences of transition, which over time will be invaluable in providing vital information to help improve services and support.

Anyone in Scotland can use Compass free of charge, whether your local authority area is using Principles into Practice or not. To sign up to the right version for you, go to: www.compasslaunch.scot

WelcoMe

WelcoMe is a web-based application which helps make sure that staff working in public facing organisations are prepared to meet and greet all disabled visitors. WelcoMe's enhanced communication tools connect person-facing teams with disabled customers.

Businesses build profiles about their customer journey, customers share their accessibility profile, and WelcoMe shares quick-to-digest information on best practices to meet individuals' bespoke needs. The platform's in-the-moment training means there is no guesswork in identifying who may have additional support needs, and how to give them a fantastic experience.

WelcoMe (wel-co.me)

Enable Works – Stepping Up using Virtual Reality tool Oculus

Stepping Up is an innovative school transitions programme delivered across 75 schools nationally, supporting young people who have learning disabilities, autistic spectrum disorder or additional support needs to build and explore their aspirations, achieve an accredited qualification and a positive progression into employment, education and industry training upon leaving school.

Enable Scotland recently rolled out the use of Virtual Reality using Oculus for the Stepping Up programme, and this case study below provides one example of how it is positively impacting young people's engagement in the programme and personal development.

Case Study – Glasgow School

YP – Young Person

EC – Employment Coordinator

VR – Virtual Reality

YP was referred to Enable Works through their school, to take part in the Stepping Up programme in Glasgow. YP is currently in S6 at school and is exploring possible pathways for their transition from school.

YP suffers with anxiety, low confidence and requires extra processing time, when given tasks to complete. During EC's initial meetings with YP these barriers were evident. YP struggled to make eye contact and EC noticed that they did not feel comfortable if asked to speak when other people were around, whether that be staff or peers. When asked to engage in conversation, YP could frequently be seen looking around the room to check who else was there and potentially overhearing the conversation.

When reflecting on this, EC's short-term aim was to make YP feel as relaxed and comfortable as possible during their sessions, as this would encourage more honest conversation and allow EC to deliver the support which will reflect their needs and interests. Patience and encouragement whilst getting to know the YP was key during initial meetings. EC was patient with YP and allowed the extra processing time required when asking questions or discussing ideas. Time was taken to complete ice breaker activities to get to know YP.

One week, EC delivered a workshop introducing the use of VR headsets. This proved to be a very positive experience for YP. YP had never used a VR headset before, so

felt anxious around trying it out initially. EC recognised their concerns and so asked another pupil, who knows YP, to try using it first. The activity was streamed onto EC's phone, so YP could see how it worked. Luckily, this helped put YP at ease, and they were then willing to try it themselves. YP thoroughly enjoyed using the headset, and it proved to boost their confidence levels. Most importantly, YP left that session with a smile on their face and was excited to return to their session with EC the following week.

From that initial introduction, the YP has since been able to access the VR headset and software to access many employability resources for building confidence and improving skills. EC delivered a trial of a new application called Body Swaps, which allows YP to practice interview skills. Questions can be tailored to any job role and YP can practice answering interview questions to a panel. These mock interviews through VR offer an immersive experience which allows YP to practice in a safe environment and gain skills and confidence which can be vital to successful interviewing.

Since the introductory workshops, and the ongoing use of the VR headset, YP no longer answers using one-word responses, but provides details to their EC and has even started to ask their own questions independently. EC is noticing YP's confidence and communication skills improving each week.

YP will continue to take part in the Stepping Up programme throughout their final year of school. Next steps for YP are CV building, exploring future pathways (including workplace visits/work experience), community impact projects, team building skills and continuing to build confidence and feeling less anxious. YP is expressing an interest in Computing and is considering applying for a computing course at college next year.
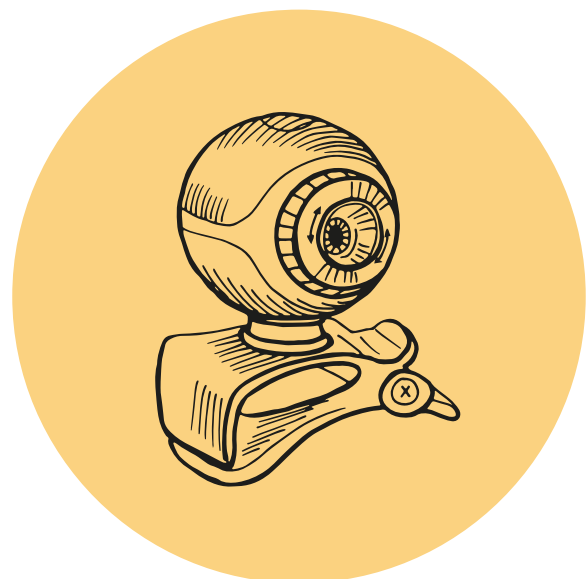
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