

Toolkits for supporting people with learning disabilities to use technology:

OVERVIEW



This overview has been written by Jane Seale with contributions from Creating Connections members.

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If you are interested in using the toolkits in your own homes, organisations or contexts please contact the author at jane.seale@open.ac.uk.



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1. Definitions of terms



Learning disability

We are using the label 'learning disabilities' to refer to some form of difficulty with experiencing and acquiring new information, which typically starts in childhood and impacts on a persons' ability to cope independently. The toolkit has also been developed in the context of supporting adults with learning disability to use technology, where adult is understood to be aged 18 or over. We acknowledge that adults with learning disabilities have a wide range of support needs and that sometimes will need help from a trusted advocate such as a family member who communicates and advocates on their behalf.



Technology

We are using a broad definition of technology in order to capture all possible kinds of support that might be provided to people with learning disabilities. For example, technologies that support communication with others, access to information or services or engagement in leisure, educational and therapeutic activities. Typical examples of technology include mobile and Smart phones; tablets, personal computers and laptops; video conferencing apps such as Zoom, Skype and WhatsApp; the Internet and apps available online such as YouTube; social media apps such as Facebook and Twitter; games consoles; MP3 players and other devices that play stored music.



Technology use

From our research and experience we know that having access to technology is not enough to ensure that people with learning disability are able to use it in the ways that they want to. Access is needed, but on its own it is not enough. To put it bluntly, we have seen too many examples where a tablet or similar device has been bought by/for a person with a learning disability and then placed in a cupboard by a care home or supporter and never used. Yet the fact that the person 'has' a tablet is used as a reason to shift attention away from concerns regarding digital exclusion. Therefore, in our toolkit whenever we talk about a person with learning disability using technology what we mean by

use is: The person has access to technology AND can use the technology if they want to. Sometimes in our toolkit we will talk about successful use. By successful use, we do not necessarily mean that the person can use technology independently. Rather we mean that the person, can, with support if needed, use technology in ways that are important and meaningful to them.



The rights of digital inclusion

We often talk about the rights of people with learning disabilities to be included in society and their local communities. There is a growing understanding that our ability to participate in society and communities is heavily influenced by our ability to use technology. Therefore, when someone is able to access and use technology this is sometimes called digital inclusion. When there are lots of barriers to someone being able to use technology, this is sometimes called digital exclusion. In this toolkit we talk about the right of people with learning disabilities to be able to use technology and their right therefore to be digitally included.



Supporter

We are using the term 'supporter' as an overarching term that refers to anyone who supports a person with a learning disability to live as independently as possible. These supporters may be paid or unpaid. Supporters therefore include formal and informal carers; formal and informal advocates; employees and volunteers of self-advocacy organisations; employees and volunteers of learning disability and related charities; parents and siblings of a person with a learning disability; friends of a person with a learning disability; day service providers; health and social care providers and education, health and social care professionals



Support

When we talk about support, we understand that everyone's need for support are different. Some people with learning disabilities need very little support, others need a lot. The same is true of support to use technology. Some people with learning disability will be able to use technology successfully with no support, some with a little support, and some with a lot of support. In the context of the toolkit, we argue that three things are more important than the amount of

support a person with a learning disability receives. Firstly, whether wherever possible they have been supported to make informed decisions about whether or not they want to use technology, and what they might use technology for. Secondly, whether they are supported to be active rather than passive users. An example of support to be a passive technology user is where the supporter switches on the device and logs in for the person, rather than supporting them to do it themselves. Thirdly, that where a person is unable to communicate or advocate for themselves, any support provided is based on accurate, up to date knowledge of their needs and desires rather than assumptions.



Framework

We are using the term framework to mean a set of ideas or facts that provide a foundation or a structure for something. In the context of people with learning disabilities and their use of technologies we are offering a framework of beliefs and knowledge, derived from our research and experience, that we think underpins effective support. We use this framework to structure our toolkit.



Toolkit

We are using the term toolkit to mean a set of resources that can guide practice. In our toolkit we provide a framework, a set of suggested actions, case study examples, links to online resources and a planning and evaluation tool.

2. Introduction

This toolkit is the result of a partnership between Professor Jane Seale at the Open University and members of the Creating Connections project. During the pandemic both partners have been focused on how technology can help people with learning disabilities to keep connected and stay well and what needs to happen so that people with learning disabilities can use the technology to keep connected and stay well.

The Keeping Connected and Staying Well project

[The keeping connected and staying well project](#) wanted to find out what, if any, support people with learning disabilities have received to enable them to use technology to keep connected and stay well during the pandemic. In order to find out the project conducted an online survey of supporters and also interviewed supporters and people with learning disabilities. The project was led by Jane Seale.

The Creating Connections project

[The Creating Connections project](#) is a partnership between SeeAbility, Learning Disability England (LDE) and their members. It is a 6-month rapid response programme, recruiting local volunteers and deploying peer supporters to help increase the network of support and social connections for people with disabilities most at risk. The programme lead is Veronica Mulenga.

Both projects have found that having good support is essential for enabling most people with learning disabilities to use technology but that not all supporters are currently providing this support. It was felt therefore that it might be helpful to develop a toolkit that could offer a structure to guide the development of technology related support practice. The toolkit that we offer in this document has been co-produced by both partners. In addition Jane Seale has shared the toolkit with participants of the Keeping Connected and Staying Well project, to see if made sense to them and also to offer them opportunities to share examples that could be incorporated into the toolkit.

How to use the toolkits

We have created three toolkits to help people with learning disabilities, supporters, managers and funders to think about and plan how best to support people with learning disabilities to use technology. Although much of the content of the toolkits has come from our experience of the pandemic, we think that they can and should be used after the pandemic. In other words the toolkits are relevant for any time a person with a learning disability might want to use technology, not just in a pandemic. All the toolkits are underpinned by a common framework of core beliefs and knowledge and we encourage you to look at the framework alongside the toolkits. Therefore we have created four separate documents:

1. A framework for thinking about the practice of supporting people with learning disabilities to use technologies. In this document we describe and explain a set of core beliefs and knowledge that we think underpins effective support for using technologies.
2. Supporting people with learning disabilities: Toolkit for people with learning disabilities: We provide tailored guidance and resources for people with learning disabilities, supporters and managers.
3. Supporting people with learning disabilities: Toolkit for supporters: We provide tailored guidance and resources for supporters.
4. Supporting people with learning disabilities: Toolkit for managers: We provide tailored guidance and resources for managers.



3. Why do we need toolkits for supporting people with learning disabilities to use technology?

Our research and experience indicates that there are five main reasons why we need toolkits for supporting people with learning disabilities to use technology:

1. Using technology can have a positive impact on the health and well-being of people with learning disabilities.
2. Being able to access and use technology is a basic human right.
3. Many people with learning disabilities are not being supported to access and use technology and are therefore digitally excluded and denied their human rights.
4. People with learning disabilities want to use technology and, with support, are able to become competent and confident technology users.
5. People with learning disabilities have the right to be supported to make informed decisions about whether they want to use technology.

3.1 Using technology can have a positive impact on the health and well-being of people with learning disabilities

The covid-19 pandemic has greatly influenced the production of our toolkit for supporting people with learning disabilities to use technology. During the pandemic we have seen how many people, faced with the prospect of working at home, not being able to meet up with friends or family, or unable to go shopping for food or other essentials have turned to technology to help them achieve these tasks remotely. In the early stages of the pandemic however, it was not clear whether people with learning disabilities were also using technologies, what the impact of using technologies on their health and well-being was and what, if any, support people with learning disabilities were receiving to enable them to use technology to keep connected and stay well during the pandemic. In order to find out, in the summer of 2020, an online survey of supporters was conducted, alongside interviews with supporters and people with learning disabilities (Seale, 2020). The findings revealed that:

- For those people with learning disabilities who had access to technology during lockdown, being able to use technology had a positive impact on their mental health, well-being and connectedness.
- One of the most important reasons that people with learning disabilities were able to access and use technology was because they either had 'in-home' or 'remote' support.

- There were, however, many people with learning disabilities who did not have access to technology and/or any support to access and use technology.

In a survey of people with learning disabilities and family carers or paid support staff about the experiences of adults with learning disabilities through the covid-19 pandemic results revealed that technology was helping adults with learning disabilities who did not live with their partner to stay in touch. Some also shared that during the pandemic they had improved their technology/digital skills which had helped them stay in touch with other people or do their jobs (Flynn et al. 2021). The covid-19 pandemic has therefore opened many people's eyes to the potential benefits that using technology can have for people with learning disabilities, However, learning disability groups are clear that technology needs to be a part of everyday life, not just life in a pandemic: "Technology needs to be a part of life for people, not just a stop gap during the pandemic" (Learning Disability Wales, 2020).

3.2 Being able to access and use technology is a basic human right

The experience of living through the 2020 covid-19 lockdowns and trying to support people with learning disabilities has led some to conclude that being able to access and use technology is a basic human right:

"I think that everybody has the right to internet. And that is just something [...] we voice quite a lot. [...] from the top down everybody's kind of feeling the same, that it should be a human right (quote from supporter who was interviewed for Seale 2020 study)

Usually, when we talk about our human rights, we talk about the rights we have to expect to be able to live a normal or ordinary life; in other words, the rights we expect to have when there is not an extraordinary, global pandemic. There is general agreement, that in our current times, a normal or ordinary life involves being able to access technology. Increasingly, our society is 'digital by default'. We need to be able to access technology, particularly the Internet, in order to access social services (e.g. ask to see a social workers); health services (e.g. book GP appointments and request repeat medications) and financial services (e.g. access bank accounts, pay bills, receive benefits). Shops, retail outlets and other services are moving increasingly online. Technology use is central to everything we do, and therefore central to living a normal life. However, many researchers have identified that people with people with learning disabilities are less able than many other people in society to access and use technologies and are therefore not being supported to live a 'normal' life (Agren, Kjellberg & Hemmingson, 2019; Lussier-Desrochers et al. 2017). Some people have gone further and argued that being able to access and use technology should be enshrined in human rights legislation. Indeed

some of the existing Articles of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006) do already appear to apply in some way to being able to access and use technology. For example, Article 9 of the convention focuses on Accessibility, with the aim of enabling “persons with disabilities to live independently and participate fully in all aspects of life”. As the digital world forms an increasing aspect of people’s normal everyday lives, so equal access to the digital world by all members of society arguably is arguably a human rights issue. In another example, accessing information via technology and self-determination over what to access in the digital world appears to be encapsulated within Article 21 of the UNCRPD, which talks about “Freedom of expression and opinion, including freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice” (Seale and Chadwick, 2017).

3.3 Many people with learning disabilities are not being supported to access and use technology and are therefore digitally excluded and denied their human rights

There are many reasons why people with learning disabilities are often unable to use technology. Some more obvious than others. Obvious reasons that tend to be talked about are lack of access to technology and not knowing how to use technology. However, before the covid-19 pandemic several researchers argued that a major reason that people with learning disabilities are excluded from the benefits that using technology can offer them is that supporters (e.g. parents, carers and other professionals) are often unable or unwilling to facilitate access and support sustained use of technology (Seale, 2014; Sorbring, Molin & Löfgren-Mårtenson, 2017). The pandemic has reinforced this argument. For example in November and December 2020 Lewisham Speaking Up (2019) interviewed people with learning disabilities and their supporters in order to find out what barriers people with learning disabilities face when getting online and the support they need to get online. They found that many people with learning disabilities in Lewisham did not have access to suitable devices, reliable broadband or support to use digital technology. The report concludes that being digitally connected is important, particularly during the covid pandemic and that ‘future proofing’ services and support is vital. Research by Seale (2020) into what kind support was being offered to people with learning disabilities during the pandemic revealed that effective support, when it existed could be characterised as speedy, evolving, creative and fearless. Those supporters who were enabling people with learning disabilities to access and use technologies were not afraid to ‘give it a go’, even when they were not sure if it would be successful and were willing to keep trying and problem-solve when then things did go wrong. It is our intention that our proposed toolkit of support will capture to some extent these important practices.

3.4 People with learning disabilities want to use technology and with support are able to become competent and confident technology users

A major reason why we feel there is a need for a toolkit for supporting people with learning disabilities to access and use technologies, is because it is clear that many people with learning disabilities want to. Research has shown that many people with learning disabilities are highly motivated to use technology and are able to become competent and confident technology users. For example, Jane Seale conducted a study with two people with learning disabilities: Ajay Choksi and Karen Spencer (Seale, Choksi and Spencer, 2019). Both Ajay and Karen were experienced and confident technology users. Ajay works in a university research centre, helping other people with learning disabilities to use multimedia. Karen uses a laptop and mobile phone and with support has learnt how to program and set up websites. Together, Jane, Ajay and Karen worked with eight people with learning disabilities who shared how they used technology in their daily lives. Some people used technology to communicate with family and friends, some played games and others used technology to follow their own leisure interests such as being a DJ.

The covid-19 pandemic has been a massive driver that has stimulated many people with learning disabilities and their supporters to try using technologies when otherwise they would not have thought to do so. One major benefit of this is that it has opened up many people's eyes to what people with learning disabilities can achieve through their use of technology. Seale (2020) reported how many participants in her study spoke of how the successful use of technology by people with learning disabilities had revealed to others how capable they were and what it was possible for them to achieve. The achievements mentioned were varied and included being able to explain to a supporter how to use Zoom; having the confidence to create a quiz and host it on Zoom, holding trustee meetings online, filming lockdown experiences and putting them online and creating or participating in YouTube videos. Similar achievements are shared in the book "Peter & Friends Talk About Covid-19 And Having A Learning Disability And/Or Autism" (Cronin et al. 2020).



3.5 People with learning disabilities have the right to be supported to make informed decisions about whether they want to use technology

We are not arguing that all people with learning disabilities want to use technology. We understand that some people with learning disabilities do not want to use technology. Sometimes this is because they simply have no interest, sometimes this is driven by fear. For example, fear of the costs involved in being online or fear of online bullying. However, we do argue that all people with learning disabilities should be supported to make informed decisions about whether or not they want to use technologies. For example, if their reason for not wanting to use technology is because of fears for online safety, it would be reasonable to expect a supporter to share and model strategies for staying safe online and to encourage the practising of those strategies before any final decision not to use technology is made.



4. Who are the intended users of the toolkits for supporting people with learning disabilities to use technologies to keep connected and stay well?

We hope the toolkits will be useful for the following groups of people:

1. People with learning disabilities
2. Supporters
3. Managers and funders of support services.

4.1 People with learning disabilities

In some situations people with learning disabilities (and/or their family) are able to have a say in who supports them and how they are supported. Examples include:

- Preparing presentations or information about themselves that is shared with people who have applied for a job as a supporter
- Sitting on interview panels for supporters
- Directly employing a supporter, through for example Direct Payments.

People with learning disabilities may find it helpful to use the toolkit for people with learning disabilities to help them think about:

- The kind of support they expect from their supporter
- The kind of information they share with supporters about whether they want to use technology, how they want to use technology and the things they find easy and difficult about using technology.

4.2 Supporters

We are using the term 'supporter' as an overarching term that refers to anyone who supports a person with a learning disability to live as independently as possible. Supporters therefore include:

- formal and informal carers
- formal and informal advocates
- employees and volunteers of self-advocacy organisations
- employees and volunteers of learning disability and related charities
- parents and siblings of a person with a learning disability
- friends of a person with a learning disability
- day service providers
- health and social care providers
- education, health and social care professionals.

It is important to be aware that sometimes these supporters will be working with the person with a learning disability in a face-to-face situation, typically in their own home. We call this kind of support to use technologies 'in-home support'. Sometimes, these supporters are not working in a face-to-face situation. Instead, they are providing their support through telephone calls, or through online methods such as email, Facebook messenger, WhatsApp or Zoom. We call this kind of support to use technologies 'remote support'.

The 'lock-downs' that have happened as a result of the covid-19 pandemic mean that many supporters have found themselves having to provide 'remote support'. It is our intention therefore that our toolkit for supporting people with learning disabilities to use technologies can be applied to both 'in-home support' and 'remote support'.

Supporters may find it helpful to use the toolkit for supporters to help them think about:

- What they currently know about the technology related needs and motivations of the people with learning disabilities that they support.
- What the barriers are that are preventing the people with learning disabilities that they support from using technology and which of those barriers they can provide support to overcome.
- The nature and level of support to use technology they currently provide to people with learning disabilities and whether and how this might need to change.

It may also be useful to read the toolkit for people with learning disabilities because many of the suggested activities involve a supporter and there are links to useful resources that can be usefully shared between people with learning disabilities and supporters.

4.3 Managers and funders of support services

Many people that we are calling supporters are employed by some kind of organisation or service. This might be a self-advocacy or advocacy organisation, a learning disability charity, a day service, a care home or residential home, a supported living organisation, a school or college, a local authority or an NHS Trust. These supporters therefore do not work on their own. They have managers who organise and supervise what they do. Often there are funders who pay for the support being provided and check the quality of that support in order to decide whether to keep paying for it. If people with learning disabilities are not getting effective support to use technologies, we would argue that managers and funders of support services have a responsibility to make sure that this changes.

Managers and funders of support services may find it helpful to use the toolkit to help them think about:

- What their organisation or service does to make sure that they employ or recruit supporters who are willing and able to support people with learning disabilities to use technology
- What induction, training and professional development opportunities their organisation or services offers to ensure that their supporters can develop the beliefs and knowledge necessary to provide effective support for using technology.
- Whether the organisation or service policies and processes encourage or discourage their supporters to support people with learning disabilities to use technology.

It may also be useful to read the toolkits for people with learning disabilities and supporters in order get an overview of what activities are being suggested for them to engage in and to plan how these can be supported.



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