

Digitally Inclusive Support Practices for People with Learning Disabilities: The Role of Ethics and Beliefs

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Abstract. In this chapter, I will discuss whether and how support practices, particularly those in supported living and residential care settings, might be informed or influenced by ethical codes or a set of beliefs that enables support workers to balance the potential benefits of using technologies (i.e. digital inclusion) with the potential risks (i.e. online abuse or loss of privacy). I will draw on research and knowledge exchange work I have conducted with a range of supported living and residential care services to consider whether and how ethics and beliefs can address the risk of digital exclusion and inequalities as well as counter an overly risk-averse culture.

Digitale inklusive Unterstützungspraktiken für Menschen mit Lernschwierigkeiten: die Rolle von Ethik und Überzeugungen

Zusammenfassung. In diesem Kapitel werde ich erörtern, ob und wie Unterstützungspraktiken, insbesondere in Einrichtungen des ambulant-betreuten und stationären Wohnens, durch ethische Kodizes oder eine Reihe von Glaubenssätzen informiert oder beeinflusst werden könnten, die es den Mitarbeiter*innen ermöglichen, die potenziellen Vorteile der Nutzung von Technologien (z. B. digitale Inklusion) mit den potenziellen Risiken (z. B. Online-Missbrauch oder Verlust der Privatsphäre) abzuwägen. Ich werde mich auf die Forschung und den Wissensaustausch stützen, den ich mit einer Reihe von Diensten für ambulant-betreutes und stationäres durchgeführt habe, um zu prüfen, ob und wie Ethik und Glaubenssätze das Risiko der digitalen Exklusion und Ungleichheit berücksichtigen und einer übermäßig risikoscheuen Kultur entgegenwirken können.

1 Introduction

The focus of this chapter is the role of ethics and beliefs in supporting people with learning disabilities who live in supported living and residential care settings to use digital technologies. Broadly speaking, people with learning disabilities (also known as intellectual disabilities or intellectual and developmental disabilities) have some form of difficulty experiencing and acquiring new information. This difficulty is described as starting in childhood and results in delays in reaching developmental milestones. This difficulty also impacts people's ability to cope independently, which means that when many reach adulthood, they continue living with their family or move into supported living or residential care settings (Seale 2022). Those who move into supported living or residential care settings are reliant on support from rehabilitation and social care staff to access and use technologies in their daily lives. Currently, the practice of supporting people with learning disabilities to use technologies is underpinned by two competing risk discourses. A discourse regarding the risk of being digitally excluded and a discourse regarding safeguarding people with learning disabilities from the potential risks of using technologies.

1.1 The risk of digital exclusion and inequalities

When practitioners and researchers talk about the potential of technology and what it can offer people with learning disabilities, a wide variety of educational, social and health aspects are highlighted. For example, learning independent living skills such as wayfinding, shopping, cooking, and managing money; being able to communicate and interact with others and tracking and monitoring fitness and health (Seale 2022). However, despite the potential for technology to facilitate positive experiences and outcomes for people with learning disabilities, we know that many of them are not able to benefit from this potential (Norman et al. 2016; Seale and D. Chadwick 2017). People with learning disabilities are lagging behind the general population in that they have less access to devices, are using the Internet in less varied ways, and feel least included in the digital society (Alfredsson Ågren, Kjellberg, and Hemmingsson 2020a, 2020b; Johansson, Gulliksen, and Gustavsson 2021). They are, therefore, at risk of being digitally excluded. This risk is particularly heightened if they live in supported living or residential care settings (Seale 2020).

Evidence from a study I conducted in 2020 called *Keeping Connected and Staying Well*, indicates that a major reason people with learning disabilities are experiencing such digital inequalities is that access to technology is not prioritised by supported living and residential care providers (Seale 2020). For example, one issue that participants in the study frequently mentioned was that many care and residential homes did not have the technology or all the components required to enable residents to get online and stay reliably connected:

I think if I'm honest we struggled to get people on board. Partly because they didn't have access, partly because of the situations they were in. Like supported living didn't have access or didn't have a laptop or couldn't use the Internet.

Some participants shared examples of how, in some homes, whilst technology was present, it had been provided for staff use only to enable them to undertake their administrative tasks:

I was told that often the manager of the home had the laptop for their administration and that was all they had. So the residents didn't have any access and didn't have any equipment. So that seemed to be one thing that was holding them back.

Examples were also shared of how people with learning disabilities needed to seek permission to use staff computers or computers in communal areas:

So all the communal computers, they have to get permission and they have to get help to set it up. And sometimes that is quite difficult, because the staff aren't always about. So that's really difficult for lots of people because staff could be busy or not have time or whatever and so they lose out because of not connecting to a computer, which is really sad.

1.2 Safeguarding and risk aversion

The new millennium has seen the emergence of a *risk culture* where perceptions of the vulnerability of people with learning disabilities have dominated the way those who support them think about their practice (Seale, Nind, and Simmons 2013). This has resulted in a focus on safeguarding, particularly in relation to the perceived risks of using the Internet, such as being the victim of online abuse or scams (D. D. Chadwick 2019; Seale 2014). Original iterations of safeguarding practices reflected a desire to balance the benefits of technology use, such as digital inclusion, with the risks. However, this very quickly developed into a practice that focused largely on risks rather than benefits.

For support workers, there is evidence that this risk aversiveness is heavily influenced by their perceptions of risk (Sorbring, Molin, and Löfgren-Mårtenson 2017; Clifford Simplican et al. 2018; Ramsten and Blomberg 2019). There is also evidence that there are significant differences in the risk perceptions of people with learning disabilities and their support workers (Chiner, Gómez-Puerta, and Cardona-Moltó 2017) and that sometimes, in order to avoid being barred from using technology, young people with learning disabilities hide their technology use from their support workers (Löfgren-Mårtenson 2008). For service providers funded by local authorities, this risk aversiveness is motivated in part by a desire to avoid sanctions or recriminations if people with learning disabilities are harmed as a result of their online activities. This often results in people with learning disabilities being prevented or discouraged from using technologies at all (Seale 2022).

In this chapter, I will discuss whether and how support practices, particularly those in supported living and residential care settings, might be informed or influenced by ethical codes or a set of beliefs that enables support workers to balance the potential benefits of using technologies (i.e. digital inclusion) with the potential risks (i.e. online abuse or loss of privacy). In doing so, I will draw on interviews that I have conducted with a range of support workers as part of the *Keeping Connected and Staying Well* study and subsequent knowledge-exchange work with a consortium of learning disabilities organizations called *Creating Connections* which included supported living and residential care services (Seale 2020, 2022, 2023).

2 The role of ethics in supporting people with learning disabilities who live in residential care settings to use digital technologies

Supporting people with learning disabilities to use technologies is about balancing the potential benefits against the potential risks. This is what ethical codes of practice do. It would seem logical, therefore, to expect that support workers would have some kind of code of ethics to draw on to help them engage in this balancing act. However, my review of the literature would suggest that this is not the case.

One of the earliest examples of empirical work in the field of assistive technology (AT) and residential care is the TATE project which ran between 2004 and 2007 and was led by a UK service provider for people with learning disabilities, with partners in Hungary, Spain, and Latvia. One strand of the project sought to work with AT manufacturers to develop and install new AT in the homes of people with learning disabilities. In reflecting on the experiences of the TATE project, Barnard and Stephen Beyer (2009) report that they were surprised at the lack of ethical frameworks for the provision of personalized technology by local authorities; noting that there was no “national or European standard, with an agreed ethical code to guide providers, commissioners and manufacturers in delivering solutions that balance safety, risk, independence and quality of life.” (p.56). In the absence of an ethical framework, the TATE project sought to develop an approach whereby AT would be provided if it fitted into the accepted assessment and support plan of the individual.

In order to address the lack of an ethical framework that is specifically designed to address the provision of technologies for people with learning disabilities, Perry, S. Beyer, and Holm (2009) proposed that Beauchamp and Childress’s (2001) health ethics framework be adapted. They also argued that because it has already been used to consider the ethical issues associated with the use of AT and telecare with people with dementia, it could be equally useful for consideration of the ethical issues for people with learning disabilities. Beauchamp and Childress described four major ethical principles: respect for autonomy, beneficence, non-maleficence, and justice. Autonomy relates to the self and the right of the individual to make choices in alignment with their beliefs, values, and preferences. Beneficence is the principle of working for the benefit of the individual. Non-maleficence is the principle of not causing harm as a result of an intervention (or lack of). Justice relates to coming to fair and just decisions when balancing conflicting needs or principles. The question of distributive justice can arise when resources are limited within a healthcare setting and healthcare professionals find themselves trying to make challenging decisions about what constitutes fair access to resources (Beauchamp and Childress 2001).

To promote autonomy, Perry, S. Beyer, and Holm (2009) suggest that AT and telecare could be used to facilitate the teaching of skills which might promote increased independence. In addition, smart home technology may increase independence if it results in reduced dependence on support staff for assistance. Since many people with learning disabilities have difficulties retaining information, O’Broilcháin (2018) suggests that technologies that can supply knowledge in forms that are more easily understood (e.g., maps, guides, reminders) will enhance autonomy for people with learning disabilities. However, if the information is overly simplified, there is a risk that knowledge will be misrepresented or distorted to such an extent that they will not be able to

make genuinely informed decisions. With regards to beneficence, Perry, S. Beyer, and Holm (2009) propose that AT and telecare may be beneficial to an individual if it promotes access to information, entertainment, social contact, skills development, and decreases dependence on support staff. With regards to non-maleficence, Perry, S. Beyer, and Holm (2009) acknowledge that some AT and telecare may prevent harm (e.g., carbon monoxide detectors), and some may cause harm (e.g., faulty or unreliable technology). In illuminating the principle of justice, Perry, S. Beyer, and Holm (2009) suggest that the costs of installing AT in a residential service could be justified if it frees staff time to support those whose needs are greatest. However, in a service where there are constrained resources, it may not be fair to meet all of the AT needs of one person if it means there will not be enough resources to meet the AT needs of other service users.

2.1 Ethics and the risk of digital exclusion and inequalities

Focusing on the lack of current market interest in providing useful or necessary technologies to people with learning disabilities, O’Brolcháin and Gordijn (2019a) argue that people with learning disabilities run the risk of being on the wrong side of the digital divide, which may further marginalize them. They position this as an issue of distributive justice. They also consider the implementation of smart homes and telecare and the implications this has for the digital inclusion of people with learning disabilities with regard to denying opportunities for autonomy and choice (O’Brolcháin and Gordijn 2019b). They argue that people with learning disabilities may not be competent enough to give informed consent to the loss of privacy that is inherent in smart home technology. In addition to the employment of advocates or surrogates who can make decisions in the best interest of the person, O’Brolcháin & Gordijn propose that smart home designers build dynamic privacy protecting measures into smart homes. One element of dynamic privacy protection is that monitoring and recording systems would have adjustable privacy settings that are sensitive to different spatial, social and activity contexts. A second element is to determine who has access to the data and what level of access they have. They also argue that people with learning disabilities should be involved in making the decisions regarding the privacy protections they want programmed into the smart home systems. Finally, O’Brolcháin & Gordijn argue that for a dynamic privacy protection system to function ethically, it will be necessary for rolling consent to be acquired, for example, through accessible electronic consent forms that are built into tablets or computer screens and displayed in places such as hallways. Although O’Brolcháin & Gordijn have raised some interesting issues, just a few empirical studies have explored whether these issues arise in reality, how people with learning disabilities and their support workers react to them, or what solutions have been trialled and evaluated (Woensdregt et al. 2020) (2020; Rasouli et al. 2021).

With regard to digital inequalities, some ethicists have considered whether and how people with learning disabilities should be treated differently from others. For example, Wasserman discusses whether protective measures should be put in place to prevent people with learning disabilities from going online and running the risk of loss of privacy (25). Wasserman suggests that norms of privacy are different online compared to real life. What might have been considered inappropriate disclosure of information in the previous century may be accepted or even expected in current online

situations. Wasserman therefore proposes that people with learning disabilities should be supported to make their own informed decisions about how much risk they are willing to take in revealing personal information about themselves. They argue that it would be ‘disrespectful to impose a more restrictive standard of personal disclosure on people with [intellectual disabilities] than on others’ (p.225).

2.2 Ethics and risk aversiveness

Ethics literature does not explicitly address the pros and cons of adopting an overly risk-averse approach to supporting technology use by people with learning disabilities. However, an influential study by Chalghoumi et al. (2019) sparked an important debate about the potential of people with learning disabilities to manage their own risk when online. Chalghoumi et al. (2019) conducted three semi-structured focus groups with six people with learning disabilities about their use of Information Technology (IT) and their perceptions regarding the benefits of using IT. All of the participants perceived that using IT had benefits, particularly with regard to increasing their autonomy. However, although they understood the concept of privacy and the need to be concerned about protecting privacy in real-life settings, they did not translate this awareness to online settings. Despite these findings, Chalghoumi et al. (2019) did not call for a raft of protective measures that might run the risk of preventing people with learning disabilities from going online at all. Instead they suggested, that as they were aware of privacy issues and adopted adequate protective measures in real-life, with the right education and tools people with learning disabilities had the potential to transfer their privacy protecting behaviours to their online activities. They also called for further research and action in order to support people with learning disabilities to understand and balance the benefits and risks of being online.

3 The role of beliefs in supporting people with learning disabilities who live in residential care settings to use digital technologies

In an attempt to counter the dominance of risk-averse support practices that can result in excluding people with learning disabilities from benefitting from using technologies, I have proposed that support practice should be underpinned by a possibility-focused framework that:

- seeks to identify possibilities for positive outcomes
- manages risk in order to decrease the possibility of negative outcomes
- involves adults with learning disabilities in decisions about possible outcomes of technology use
- draws on the potential of both adults with learning disabilities and support workers.

I have argued that this practice will be influenced by a range of factors, including risk perceptions and beliefs about the possible benefits and risks of using technologies (Seale 2022, 2014).

A belief is a statement or argument that a supporter holds true or acceptable. In the context of supporting people with learning disabilities to use technologies, the focus is on beliefs that are actively thought about (core beliefs) rather than beliefs that we

might say we have if we are asked; but have never previously thought about (dispositional beliefs). Results from the *Keeping Connected and Staying Well* study indicated that the beliefs held by support workers can indeed influence their practice; for example, beliefs about the role of support workers and the value of technology (Seale 2020). Further consultations with the *Creating Connections* Consortium resulted in a proposal for a set of five core beliefs that underpin practice that supports adults with learning disabilities to access and use technologies (see Table 1). Enacting these five core beliefs in practice may enable support workers to balance the risks of not using (digital exclusion) technologies with the risks of using technologies (safeguarding).

3.1 Beliefs that address the risk of digital exclusion and inequalities

Many researchers position digital exclusion and inequalities as a human rights issue and as a consequence, turn to the Convention on the Rights of Persons with Disabilities (CPRD) (United Nations 2006) for indicators that taking appropriate action to reduce digital exclusion is expected of those governments who sign up to the convention (Seale and D. Chadwick 2017; Borg, Larsson, and Östergren 2011). Analysis of the content of the CPRD indicates that technology is explicitly referred to in seven of its fifty articles (28). Seven articles relate to access to and use of technology. For example, Article 4 refers to promoting the availability and use of AT, and to provide accessible information about AT. Evidence from *The Keeping Connected Study* indicated that some practitioners held beliefs that reflected those of the CPRD, that being able to access technology is a human right.

I think that everybody has the right to internet. And that is just something that's been like, we voice quite a lot. That, so yeah from the top down everybody's kind of feeling the same, that it should be a human right.

Table 1 Core beliefs that underpin practice that supports adults with learning disabilities to access and use technologies

Focus: Addressing the risk of digital exclusion and inequalities

Core Belief	Description
1. Rights	People with learning disabilities have a right to use technology if they want to. If people with learning disabilities want to use technology, they should be supported to use it.
2. Supporter role	An important part of a supporter's role is to help people with learning disabilities use technology if they decide they want to use it.

Focus: Addressing safeguarding and risk aversiveness

Core Belief	Description
3. Potential of people with learning disabilities	With the right support, people with learning disabilities have the potential to use technology successfully.
4. Informed choices	People with learning disabilities should be supported to understand the possible benefits of using technology and the opportunity to express their interest (or lack of interest) in using technology.

Members from the *Creating Connections Project* shared similar views:

People have a right to access technology if they want to. It is important for people to know their right.

When talking to me about the resistance they had experienced from colleagues and refusal to help people with learning disabilities access and use technologies, some practitioners in the *Keeping Connected and Staying Well study* hypothesized that it was because some support workers did not believe that it is was their responsibility to support use of technology:

Some support workers won't help them learn [...] I've spoken to the support worker and they've said, 'that's not my job role.' so I've kind of said 'you're supposed to be supporting this person, helping them live the life they want to live.' but no, they don't want to do that.

Members from the *Creating Connections Project* shared similar thoughts and experiences. For example:

I had a phone-call with someone who was supporting someone in a shared house, and I said, 'Can you help them get online?' and they said, 'Oh no we are an old-fashioned house here; we don't do technology.'

These views resonate with the findings of Parsons et al. who observed technology related practice in nine day-service units within one organisation and concluded that services with more traditional beliefs about the purpose of service provision for adults with learning disabilities were much less likely to use Information and Communication Technologies (ICT) (Parsons et al. 2008).

Some professional organisations have identified that technology can be an important part of a person's life and therefore should be included as part of person-centred support. For example, The National Institute for Health and Care Excellence in the UK indicate that practitioners who are supporting people growing older with learning disabilities should include technology when they are planning future support (National Institute for Health and Care 2018). Most supporters, particularly those working in supported living and residential care will be familiar with the concept of person-centred care or person-centred support. This is care or support that takes into account the needs, thoughts, concerns and opinions of the individual and consulting those within their personal network such as family and friends. Key aspects of person-centred support are that it is tailored to the needs of the person and looks at the person's life as a whole (Seale 2022). Members from the *Creating Connections Project* felt strongly that that it was important for support workers to believe that technology

should be customised to ensure that all of the technology needs of a person with learning disabilities are met was really important:

It is important that we don't offer 'blanket' support options, that we use technology in a way that works for each individual person.

3.2 Beliefs and risk aversiveness

During their interviews, a number of parents and support workers in the *Keeping Connected and Staying Well study* shared with me their beliefs regarding the resilience of the people with learning disabilities they supported and their ability to assess risks or deal with an issue if it arose:

We're debating whether to buy him a new iPhone for his birthday as that's what he wants, but he leaves things. You know, he leaves things on buses and things like that, but you have to be prepared to take some risk to get the benefit of it, and the benefit of giving him a mobile phone is that if something goes wrong and he needs to phone us we can get that call. Now, I think he'd be able to FaceTime if something went wrong.

I mean I recognize that there are challenges but I just figure we have to beat them. If [...] ends up chatting with some paedophile or something like just drawing the kind of worst scenario, like he'll be like I'll figure it out I'll step in or his mum will or he'll say, 'can I go to meet this guy?' and I'll be like 'let's look into that a little more'.

Members from the *Creating Connections Project* shared examples where because a person was not currently using technology, supporters assumed that it was because they could not use it and, therefore, would never be able to use it in the future. They argued that this is not necessarily true:

It is about future potential, more than current capabilities. A few years ago, who knew that my brother would be able to Facetime and do various things on the iPad, but now he can. So it is about forward-thinking.

Some people with learning disabilities need support to make informed choices about their technology use. This is why it is important that support workers believe that people with learning disabilities should be supported to make informed choices and therefore engage in a shared decision-making process in which both the benefits and risks of using technology are considered. For example, a study that investigated the role of mobile technologies in promoting the social inclusion of adults with intellectual disabilities (Martin et al. 2021) concluded that:

Educating people with intellectual disabilities about mobile devices and apps and supporting them in making independent and informed choices about using these is of substantial importance and needs to be applied across the diverse settings in which people with intellectual disabilities operate (p.848).

Participants in the *Keeping Connected and Staying Well study* and the *Creating Connections Project* shared with me their beliefs about the importance of supporting people with learning disabilities to make informed choices about their technology use:

You're not here to be their mum, you're here to give them the fullest life that they can have which means taking this and accessing this. That's what you're supposed to be focused on them having, not focused on them being safe all the time. Because none of us are safe all the time, you know. And you're taking that away from them. And so even, like you said, they perfectly know what risk to take. They perfectly know what they're doing, they perfectly know and yet we're taking that decision out of their hands.

There is no point in asking people with learning disabilities if they want to use technology if they don't know what technology there is and what it can do.

4 Conclusions

People with learning disabilities have less access to technologies and are using them less than people without disabilities (Alfredsson Ågren, Kjellberg, and Hemmingsson 2020a, 2020b; Johansson, Gulliksen, and Gustavsson 2021). Efforts by support workers to address this risk of digital exclusion have been counteracted by efforts to eliminate the perceived risks of using technologies. In this chapter, I have discussed the influence of ethical codes and personal beliefs on the practice of support workers and the extent to which they enable support workers to balance the potential benefits of using technologies (i.e. digital inclusion) with the potential risks (i.e. online abuse or loss of privacy). More work needs to be done to build consensus around an ethical code of practice and a framework of core beliefs that the community as a whole agrees is meaningful and practical in the contexts in which they are working. Once consensus is achieved, it will be important to build the capacity of support workers to implement the codes and frameworks in partnership with people with learning disabilities.

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