

# Exploring how support workers understand their role in supporting adults with intellectual disabilities to access the Internet for intimate relationships

Jason Lines<sup>1</sup>  | Helen Combes<sup>1</sup>  | Ruth Richards<sup>2</sup>

<sup>1</sup>Staffordshire University, Stoke-on-Trent, UK

<sup>2</sup>North Staffordshire Combined Health Care, Harplands Hospital, Stoke-on-Trent, UK

## Correspondence

Jason Lines, Staffordshire University, R206 Science Centre, College Road, Stoke-on-Trent, ST4 2DE, UK.  
Email: jasonlines61@gmail.com

## Abstract

**Background:** Some adults with intellectual disabilities need support to access the Internet. This study explores how support workers understand their role in facilitating Internet access for intimate relationships.

**Method:** Eight support workers in the West Midlands of the UK were interviewed face-to-face, using semi-structured interviews and a thematic analysis was used to interpret the data.

**Results:** Three main themes emerged; social and organizational dilemmas (including sub-themes of; role and moral positioning, expectations of support, and protected and reflective space), power and position and policy dilemmas.

**Conclusion:** Support workers said that adults with intellectual disabilities should have access to the Internet for intimate relationships. There was a range of views on whether it was their job to support this. A lack of training in Internet use was highlighted.

## KEYWORDS

intellectual disabilities, Internet, relationships, support, thematic analysis

## 1 | INTRODUCTION

### 1.1 | Internet use

Use of the Internet has become an everyday occurrence for many and data from The Office of National Statistics (2018) in the UK shows widespread Internet use, from paying bills and shopping to maintaining personal relationships through social media and dating sites. Internet use is therefore increasingly seen as a basic human right (Oyedemi, 2015). However, some people with disabilities can have difficulty accessing the Internet (Dobransky & Hargittai, 2006) and there is Governmental policy on how to promote greater

inclusion for people with intellectual disabilities in Internet activities (Department for Digital, Culture, Media, & Sport, 2017).

The UK Mental Capacity Act (2005) was written to ensure that individuals, including people with intellectual disabilities, have the right to be supported in making decisions. It aimed to empower people and has been central to legal cases involving adults with intellectual disabilities and Internet use (English, 2019). In fact, adults with intellectual disabilities are accessing the Internet, although research has tended to focus on Internet safety and risk prevention (Batey & Waine, 2015). Because some adults with an intellectual disability require support to use the Internet, it is also important to evaluate how support workers understand their role in supporting with Internet use.

This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

© 2020 The Authors. *Journal of Applied Research in Intellectual Disabilities* published by John Wiley & Sons Ltd

## 1.2 | Supporting internet use

Mencap (2020) defines the role of an intellectual disabilities support worker broadly—from cooking to enabling people to be active in their communities. The Internet brings modern challenges for support workers to enable its safe access whilst negotiating the risks, maintaining privacy and making judgements about what is appropriate and inappropriate for adults with intellectual disabilities (Chadwick et al., 2013). These challenges are intensified when the policies organizations provide to support adults with intellectual disabilities are risk-averse and provide inadequate training around Internet use (Windley & Chapman, 2010).

Darragh (2019) interviewed thirty individuals living with intellectual disabilities in Australia and found that people were accessing Internet-based social media to make friends, communicate with people and plan meetings. Darragh also found that systems and gatekeepers have a significant role in what those individuals could do. This theme of gatekeeping is noted in other research (Mason et al., 2013), which suggests that adults with intellectual disabilities can view their support workers as the “key holder” to activities, further emphasizing the role support workers play in accessing the Internet with the people they support. Sallafranque and Normand (2017) asked adults with intellectual disabilities or autism spectrum disorder about Internet use via questionnaire. Participants were all enjoying using the Internet for various reasons; however, their research highlighted the distressing experiences of Internet use for those individuals, such as being insulted, receiving threats or being targets of sexual cyber-solicitation. The need for friends, parents and support workers to help guide and support them through those experiences was important.

Attitudes of support workers may also impact on the support a person with intellectual disabilities receives. Saxe and Flanagan (2014) asked university students with support worker experience to complete a questionnaire which aimed to capture their attitudes towards the sexuality of people with intellectual disabilities. They found that views were generally liberal, although variability in attitude appeared to be linked to religious beliefs and educational background. Grieve et al. (2009) used a questionnaire to examine nursing and care staff attitudes towards sexuality for people with intellectual disabilities. They found that nursing home staff held significantly more conservative attitudes towards homosexuality and attitudes towards the sexuality of people with intellectual disabilities than community care staff. Those staff with more training were more likely to promote relationships for the people they support. There are also ethical, moral and legal dilemmas support workers face which can impact upon how they facilitate support (Dunn et al., 2010; Wilson et al., 2009).

## 1.3 | Social media and relationships

Use of the Internet to access social media websites, such as Facebook and apps such as Tinder, to develop intimate relationships has increased (Belton, 2018), although social media sites such as Facebook have been negatively reported in some research (Holmes & O'loughlin, 2014).

Hollomotz & Speak-up Committee (2009) conducted four focus groups with service users of an NHS intellectual disabilities service, which highlighted the difficulties people face when seeking the privacy to explore sexual relationships, especially when living in communal accommodation. Australian research (Darragh et al., 2017) where adults with intellectual disabilities were interviewed about their Internet use found that people could conduct themselves safely without any specific training. There are other, wider challenges for people with intellectual disabilities who are looking to engage in sexual relationships, which include issues around capacity and the law (Evans & Rodgers, 2000), the impact of social and cultural norms ascribed to people with intellectual disabilities and perceptions of their sexuality (Azzopardi-Lane & Callus, 2015), and structural and organizational rules that may also preclude facilitating relationships between service users (Lesseliers, 1999).

Support workers who are attempting to support adults with intellectual disabilities to use the Internet to explore intimate relationships may look for guidance in how to navigate the Internet alongside those they support. There is guidance with recommended Internet sites to help people to explore their sexual identity (CQC, 2019), but there appears to be less clarity about the specific role of support workers concerning social media and accessing Internet resources to build intimate relationships.

Although there is a growing evidence-base investigating the views and attitudes of support staff regarding sexuality and personal relationships for adults with intellectual disabilities, there is little research looking at how support workers understand their roles and responsibilities in facilitating their access to the Internet. Previous studies have highlighted the impact of gatekeeping on people with intellectual disabilities access to the Internet for intimate relationships; other research suggests support workers are the “key holders” to activities. It is therefore important to explore how support workers understand their role in facilitating successful access to the Internet to develop and maintain intimate relationships. As society continues to emphasize the digital world for building and maintaining intimate relationships, it is important to consider how support workers understand their role in supporting adults with intellectual disabilities to do that too.

## 1.4 | Research question

How do support workers, supporting adults with intellectual disabilities, understand their role in facilitating Internet access for intimate relationships?

## 2 | METHOD

### 2.1 | Design

This qualitative study used semi-structured interviews to guide discussion and encourage in-depth exploration of the research topic.

Participant	Age	Gender	Months as a support worker	Hours worked per week
1	32	F	120	38
2	29	M	16	42
3	38	F	108	38
4	37	F	180	38
5	20	F	14	37
6	25	M	14	37
7	35	M	13	37
8	27	F	108	40
	Mean	5 (F)	Mean	Mean
	30.38	3 (M)	71.63	38.38

TABLE 1 Participant demographics

Thematic analysis was chosen due to its flexibility and accessibility, particularly regarding making sense of collective meaning and understanding across a dataset. A participatory research methodology was used (focus group) to develop the research interview schedule. This study offers an opportunity to capture rich data about how support workers understand their role in facilitating Internet access for intimate relationships, which may have been more difficult to truly capture with quantitative methodology.

## 2.2 | Principal researcher

The researcher has worked in various roles with people with intellectual disabilities and takes a social constructionist epistemological position (Gergen, 1985). The researcher has strong views on the rights of people with intellectual disabilities and has expectations of support workers who are working with adults with intellectual disabilities. The researcher believes that paid support workers should enable people to achieve their goals.

## 2.3 | Procedure

### 2.3.1 | Ethics

Ethical approval for this study was granted by the University's Research Ethics Committee. Full, written consent was obtained from each participant before the study, and a debrief was offered afterwards. All data were anonymized.

### 2.3.2 | Focus group

Three organizations providing community-based skills and activity support to adults with intellectual disabilities were found online and approached via email to arrange a focus group to discuss Internet use. One organization responded and information sheets with

consent forms were sent through, dates were arranged to complete the focus group.

Six adults with intellectual disabilities receiving support to use the Internet for intimate relationships, and two support workers, participated in the focus group.

The focus group was held in the organization's local community centre and the planned research was outlined. Discussion from the focus group was drawn onto three whiteboard sheets, and this information was consulted when the researcher created the semi-structured interview questions. Following the focus group, questions were added about family and gender differences. The focus group helped to develop the interview questions regarding how support workers understand their role in supporting adults with intellectual disabilities to access the Internet for intimate relationships. The researcher returned to the focus group to disseminate the findings from the interviews.

### 2.3.3 | Recruitment

Eight organizations across Staffordshire and Shropshire providing support services to adults with intellectual disabilities were found online and an invitation to participate was sent. Three organizations responded.

Service managers from those organizations were sent participant information sheets and consent forms so any support workers interested in participating could read and sign the forms.

Those three organizations manage community-based supported living housing services for adults with mild to moderate intellectual disabilities. All services were staffed 24/7 and provided active support in daytime hours, with sleep-in staff providing only essential support overnight if required.

There were challenges recruiting from private organizations, as of the identified eight; four, offered to pass the matter on to their human resources department and did not contact the researcher again, one stated that the research was a "waste of time" and declined to participate.

### 2.3.4 | Participants

Eight support workers, from the three interested organizations, completed semi-structured interviews. Table 1 shows the demographic data for all participants. The inclusion criterion was more than one year's experience working as a full-time support worker (experience ranged from 1 to 15 years). All support workers were currently supporting individuals with intellectual disabilities with varying Internet competence and who were accessing the Internet for variety of purposes, mainly social media, gaming and emails. Individuals receiving support had between one and three hours per day of direct 1–1 support time. All support workers had been offered basic induction training packages, none of which included any training on supporting people in Internet use. The service managers were asked to provide guidance given to staff on Internet use, the information shared with the researcher only described personal Internet use by staff members. None of the participants had received training on Internet use and sexual relationships.

### 2.3.5 | Interviews

A semi-structured interview schedule (Appendix 1) was developed and used following the focus group. Face-to-face interviews took place in an office on the work premises. The interviews were free from interruption and lasted between 38 and 59 min.

The researcher asked participants whether they had read the participant information sheet and were happy to continue. The interviews were recorded onto a Dictaphone. Debrief sheets were given to participants at the end of the interview. All data were anonymized.

## 2.4 | Data analysis

Interviews were conducted, transcribed and analysed by the first author who followed Braun and Clarke's (2013) six-stage approach. The audio data from interviews were transcribed. The transcripts were read three times, first taking note of items related to supporting Internet use. Coding was completed by working systematically through the data through the chronology of the interview, using an excel spreadsheet to highlight large or small chunks of data relating to the research question noting a summary label, and sorted into themes and sub-themes. These themes were constantly redefined to ensure they encompassed all of the items within them and to interpret their relevance to Internet use. Supporting quotes were identified in the excel spreadsheet to support the themes generated.

### 2.4.1 | Credibility

To minimize biases in interpretation, the analytic process was taken to a qualitative research group at University and the researcher bracketed the data to reduce their bias (Tufford & Newman, 2012).

Three sections of transcripts were taken along with the codes and a thematic map to the qualitative research group at the University and themes were modified in light of their feedback. This involved between six to nine peers (Trainee Clinical Psychologists), and between one to three academic tutors (Clinical Psychologists/ PhD). Academic and clinical supervisors, both Clinical Psychologists, provided feedback on the analysis.

## 3 | FINDINGS

Three themes emerged:

1. Social and Organizational Dilemmas, containing three sub-themes;
  - a. Role and Moral Positioning
  - b. Expectations of Support
  - c. Protected and Reflective Spaces
2. Power and Position
3. Policy Dilemmas

Each theme is presented and outlined separately; however, the themes are inevitably interlinked. These themes can be organized beneath a central, candidate theme, of *how support workers understand their role*. Thematic maps provide an overview of the findings from a dataset, see Figure 1 below.

### 3.1 | Social and organizational dilemmas

This theme was central in how support workers understood their role—how they support and why they support came from how they make sense of social and organizational dilemmas. The three sub-themes; role and moral positioning, expectations of support and protected and reflective spaces, feed into and impact on this central theme.

It's horrible. Cause, that's not what you're in the job of care for. You're in the job of care to keep them safe, from harm, risk, and everything else, abuse. But from some degree you can't, you know.

Participant 1

Everyone wants to be loved, don't they?

Participant 2

I think that would be, one of the best things you could possibly do to make somebody feel that there is actually an existence outside of their, unit, their support, living in a home.

Participant 4

All participants made similar comments regarding how they make sense of these social and organizational dilemmas, as to how and

## How support workers understand their role?



**FIGURE 1** Thematic map demonstrating the relationship between the overarching theme, main themes and sub-themes. [Colour figure can be viewed at [wileyonlinelibrary.com](https://onlinelibrary.wiley.com/doi/10.1111/jar.12822)]

why people should be supported, particularly around having access to relationships. There was a feeling that everyone should be entitled to pursue and engage in relationship building, and that this belief was broader and inclusive of adults with intellectual disabilities.

### 3.2 | Role and moral positioning

This sub-theme highlights how participants varied in both their approach to the role of supporting adults with intellectual disabilities to use the Internet for intimate relationships; but also how they described that difference in other support workers, which appeared to come from an individual's moral position, rather than any specific guidance. This is linked to social and organizational dilemmas, as although there were unanimous comments about the social dilemmas—that everybody should have access to relationships; how support workers would support with this in their role differed. These differences suggest that how support workers understand their role is a continuum; from direct, physical and instructive support, to a more open and monitoring, see what happens, form of support.

Well, I wouldn't let them talk to them, I'd delete their details, they won't speak to them again if they did come up.

Participant 7

You'd be like, telling them, kind of encouraging them with what to type of things to say, but I wouldn't want it to be...me pressing that send button – its dependent on the staff and the person...it might depend

on like, your relationship with the person that you're doing, that you're gonna be supporting.

Participant 8

Participants also reflected on the differences between support workers more generally, there was a clear moral distinction between those who go “above and beyond,” and those who come in and do what needs to be done and go home. There was consideration made to the pay and prestige of the support worker role, but also a feeling that difference within support teams is inevitable.

Depending on what kind of support worker you are, you know, whether you are someone who, erm, bundles along and helps then, just, you know, they've come to be a good person. Or if you wanna try and, help move them forward and be more progressive. It depends on the staff and how well they understand the needs of the service user.

Participant 1

I feel like it's one of the extra things, like above and beyond, you know, it's part of our role to make sure they're safe and supported in everyday decision...I feel like any really good support worker strives to do (support with sexual relationships), cause its part of empowering them, isn't it?

Participant 2

Because of the nature of the pay and stuff...some people can treat it like a factory job, which might be like, not necessarily a bad thing, they come in, make

sure the service user is happy (and) go home. Others are a bit more emotionally invested in it.

*Participant 7*

### 3.3 | Expectations of support

The sub-theme of expectations of support is also linked to social and organizational dilemmas; it highlights what the support workers expectations of their role are and where those expectations come from. Some of these expectations for their role come from individual support workers' beliefs about the role, for others, it appears to be a somewhat unclear organizational or professional expectation of the role.

It's not up to us to decide how service users want to live their lives, it's up to us to help them do it, and empower them to do it.

*Participant 2*

I think my role is to help people feel comfortable that they can do everyday things, like everybody else does. But at the same time, I'm not there to encourage a relationship with somebody else, that's for them.

*Participant 5*

It's your job to support them, erm, but in a way like, is it kind of wrong to support to be helping them make a profile for example, dating, because erm, you can get strange people...it's a bit of a risk.

*Participant 6*

The expectations of the support worker participants regarding their role also appeared to fall into a continuum. This continuum appeared to range from broad, idealistic expectations to support adults with intellectual disabilities with whatever they wish to do, to something more rigid, where supporting with something like dating is not seen as within the role.

you've got the support and that's what were there for, were support workers to support people, but at the same time there is only so much we can do, under the laws, of care anyway, which is rightly so – they should have their privacy, they should have everything we take for granted.

*Participant 2*

Obviously it's down to us to try and find out if they're going to meet someone, we'd be expected to try and, you know, make sure you know where they're going.

*Participant 8*

There were also comments that support workers were "expected" to perform certain roles, and this appeared to come from an organizational or professional pressure rather than the individual's evaluation of how they should offer support.

### 3.4 | Protected and reflective space

This final sub-theme linked to social and organizational dilemmas highlighted how support workers considered the importance of support for themselves, and the impact of this on their role. Some participants discussed how their role would be to involve external professionals, such as social workers, if the support required was beyond their capacities, for one participant there was a wish for additional services. This idea of contacting external professionals was often thought about in terms of a lack of experience or training.

We have a job to support them, but we also have to be careful of our own, of what we can and can't do, so at that point I would seek advice from other people, whether that be the manager or external professionals.

*Participant 1*

...if they continue to want to take the risk, and I had a genuine concern, then I probably would go wider as well, to just say that you know, whether it all, or whether it needed to go to social workers, or whatever.

*Participant 8*

Erm, there will be an internet policy...to be honest I'm not sure if that's for staff use on the internet, or whether it's about the service users.

*Participant 1*

I know it might sound odd but maybe we could have a bit of training on that, so that we could then support them rightly, how to access it and make sure the sites they are using are safe.

*Participant 3*

...and really, we should be having training cause, its everyday life ain't it, but, that's why I'm finding it a bit difficult to answer the questions... 'cause I've never really had the training right.

*Participant 6*

There also appeared to be a lack of space for learning and training as all but one of the participant support workers highlighted a lack of training or guidance from their organization. There appeared to be a desire for this training, however, the available guidance was thought to be around Internet use for support workers, rather than

supporting adults with intellectual disabilities to use it. What was clear is that there was no training available for support workers on how to effectively support adults with intellectual disabilities to use the Internet, let alone on how to support them to use the Internet for intimate relationships.

### 3.5 | Policy dilemmas

One of the three main themes which were generated from the data-set is the idea that a support worker's role is one of continuously weighing up and making decisions on dilemmas related to policy. This theme is linked to the social and organizational dilemmas of the individual support worker and is also linked to how that support worker views themselves regarding their power and position.

It's a minefield isn't it, erm, getting somebody to the point where they're able to access that, but safeguarding them, you know, keeping them safe, and also keeping other people safe.

Participant 5

You would have to find the right level of monitoring, finding that balance between keeping people safe and giving people that independence.

Participant 7

...it would depend on the person again, and their ability to understand, like, what they're doing and what risks they're putting themselves through... if they were not aware, you'd need to tell them that there are risks that they're taking.

Participant 8

The support worker participants spoke about their role supporting adults with intellectual disabilities to access the Internet for personal and sexual relationships through a process of dilemmas. Those dilemmas included whether the person they were supporting fully understands what it is they wish to engage in, whether the person understands any danger or risk, thinking about the other people involved and finding the right level of monitoring. Support workers highlighted the difficulties of often having to decide on these dilemmas in the moment—they saw their role is to be able to do that as successfully as possible.

I'd encourage them to do anything they wanted to in life. The only thing, that, it's the risks that it involves. And do they really have the capacity to understand, how dangerous it can be for people getting in touch with them, erm, I suppose you aren't in control of the situation to keep them safe.

Participant 1

An individuals' mental capacity would have to be assessed to decide, accessing what part of the internet was appropriate, and obviously the reason they wanted to access the internet.

Participant 4

If they have the capacity to do what they want they can do tell 'em, to be aware, check what they're doing.

Participant 7

Most participants also used the term "capacity" when discussing their role in terms of policy dilemmas. It was unclear about their understanding of the term; however, it was generally used in a questioning way, for example, "do they have capacity" or "if they have capacity." The way the term was used suggested that the support workers saw it as part of their role to assess or make a judgement on a person's capacity to engage in intimate relationships online.

### 3.6 | Power and position

The final theme generated from the interviews highlights the differential power and positions between support workers within their role, particularly around risk management and supporting adults with intellectual disabilities to use the Internet for intimate relationships. This process of thinking about the risk of supporting a person to access the Internet versus the safety concerns of the person they are supporting, and others involved, was prominent in all the interviews. In some cases, the support workers felt that had the power to intervene, in others they did not. This theme is closely linked to the theme of policy dilemmas; it is a separate theme because it was spoken about in more detail and with a perceived higher level of importance than other dilemmas.

I know it sounds a bit weird, but the internet these days you've got to be careful with because people impose and make out they are somebody and they are not who they are, so sometimes it's dangerous.

Participant 3

My role would be to facilitate somebody to be able to do what they wanted to, to get their wishes, but to keep them safe from underlying harm that might come their way due to their vulnerabilities.

Participant 4

It's their choice really, the only thing I can do is to make sure they come back safe, and when they come back that they feel comfortable talking about their experience.

Participant 5



I'd feel really bad if they were to have a bad experience, but then I suppose, don't we all, it's a risk you take isn't it, on these dating sites, to whether you find somebody decent, or...a fruit loop.

Participant 3

...if anything happened, sexual wise, that wasn't a pleasant experience for them, I suppose you would take some of the blame yourself? You know, and might think, I knew what was going on and I could have stopped it, type of thing?

Participant 8

They could find out who they are, see them out, see where you are in the community, see where they live and stuff like that, could be very dangerous, could hurt them or anything.

Participant 7

...he was just genuinely talking about, we had all the conversations, he was just talking about the weather and PlayStation games, but because there was this man and he'd told him he was a young girl, he was then, splashed all over the internet - he went from being independent to not being able to go out on his own.

Participant 8

The quotes above show concern support workers have about the risk of something terrible happening to the people they are caring for, and how that makes them feel. This position of guilt or blame could limit the support an adult with intellectual disabilities to use the Internet, particularly in intimate relationships. One support worker gave an example of a person they had supported and the emergent real-world difficulties. These considerations could add another layer of potential risk in the consideration process when support workers are thinking about how to support a person online with intimate relationships.

## 4 | DISCUSSION

This study provides insight into how support workers understand their role in supporting adults with intellectual disabilities to access the Internet for intimate relationships. Support workers said that building intimate relationships was important for adults with intellectual disabilities. However, there were individual dilemmas about Internet use when making decisions on how much they believed this to be part of their role. Some support workers said that it was very much part of their role, and took an open, advising, "let's see what happens" approach; others were clear that it was not their role. Support workers are part of a diverse, wider team each holding a different perspective on what their support should be.

Research has explored how the attitudes of support workers impact upon how they support adults with intellectual disabilities to explore sexual and personal relationships (Saxe & Flanagan, 2014) and towards sexuality (Grieve et al., 2009). The central theme found in this study shows a continuum in how support workers view their roles in supporting adults with intellectual disabilities to use the Internet for personal and sexual relationships. Mason et al. (2013) found that support workers are often seen as "keyholders" whereas this study shows that the support an adult with a learning disability is given in using the Internet for personal and sexual relationships is dependent upon their support workers sense of how to best manage the moral and ethical dilemmas which are based on their experiences and expectations, not necessarily from organizational guidance or training.

Other research emphasizes the challenges and dilemmas of weighing up risk, privacy and appropriacy for support workers face when supporting adults with intellectual disabilities to use the Internet (Chadwick et al., 2013). In this study, the support workers described their role as having the ability to weigh up the situation and make in-the-moment decisions about how best to support people whilst keeping the balance between risk and safety in mind. This study also revealed that there were dilemmas about "capacity." The support workers interviewed were using this term in a way that suggested part of their role was to weigh up, or at least consider, whether the person they were supporting "had capacity" to understand and make decisions. There is an apparent lack of understanding about the Mental Capacity Act (2005) where the support workers understood it as guidance to restrict rather than enable Internet use. This has significant implications in teaching people with intellectual disabilities about the uses and abuses and of the Internet. The participants used the term to prevent them from making decisions, particularly decisions around risk, rather than decisions to promote empowerment. There is some research which has looked at support worker understanding of capacity in dementia services (Manthorpe et al., 2011) which found that staff had a varied understanding of the act, but little knowledge of specific legislative points and they recommended further training. The research is sparse about the Mental Capacity Act and the extent to which support workers who work with adults with intellectual disabilities understand it.

Managing these dilemmas appeared to be central to their role, although participants also acknowledged that there was no training or guidance from their respective organizations. Unfortunately, organizations offering little to no training or guidance for support workers was highlighted in previous research (Windley & Chapman, 2010), and remains the case nearly ten years on. Regulatory bodies such as the Care Quality Commission (2015) in the UK provide some broad guidance for organizations on the training that their support workers should be offered; however, there is a lack of specificity around supported Internet use. Whilst some established intervention approaches, such as Positive Behaviour Support, have supporting research and guidance on training needs for support workers (Lowe et al., 2007), broader approaches around supported Internet use does not.



## 4.1 | Limitations

One limitation of this study is about the participant demographic; this study only included support workers in the West Midlands and may not be representative of all support workers views. Participants were sourced from just three different organizations, there may be other organizations providing training or guidance to their staff, which have not been covered by this research. Also, the interviews were conducted in supported living environments which may have led to support workers minimizing the ethical and moral dilemmas that they may face in their work, this is arguably reflected in the comments from other service providers that the research was a “waste of time.”

Inevitably, the views and experiences of the researcher may impact on how the researcher approaches the interview process and the analysis. As a Trainee Clinical Psychologist, the researcher has professional structures in place which provide regular supervision, training and protection in what is expected from their role. Support workers, who are working with adults with intellectual disabilities, are rarely offered this level of professional structure—the focus on training and guidance from the data by the researcher may come from this professionally privileged position. Efforts were made to reduce the impact of these factors on the data analysis and interpretation; a reflective journal was maintained throughout the entire research process and the researcher also made use of several qualitative research study groups at the university, facilitated by research staff and peers, bringing data and exploring the reasoning behind theme construction. However, there continues to be a discussion on the trustworthiness of qualitative data (Elo et al., 2014) which recognizes that it is often difficult to evaluate its trustworthiness.

## 4.2 | Future research and clinical implications

It is important to explore the views and experiences of adults with intellectual disabilities who are attempting to access the Internet for personal and sexual relationships with support. As well as comparing the expectations, hopes and assumptions that adults with intellectual disabilities have about the role of their support staff in terms of supporting them to access the Internet for these purposes. If the expectations are at odds, there are implications for support workers, services and service providers who claim to promote independence and inclusivity. Exploring how organizations understand their role and responsibilities in providing support for adults with intellectual disabilities to access the Internet for personal and sexual relationships, from training staff, developing policy and guidance, to equipment and resources, is essential.

A lack of guidance and training opportunities for support workers has been found in previous research, and this study. Without this support, how support workers understand their role in helping adults with intellectual disabilities to use the Internet for personal and sexual relationships is influenced by individual beliefs, values and experiences rather than best practice. Thus, the support an adult with intellectual disabilities receives varies from service to

service, and from support worker to support worker. This research highlights the need for a clear, structured and professionally informed training programme that is available to all those who support people with a learning disability to use the Internet for personal and sexual relationships. This training programme should be developed in collaboration with professionals, support workers, organizations who provide support and adults with intellectual disabilities and should highlight individual human rights as well as legal imperatives. The themes identified in this study provided a starting point for this training—how support workers weigh up and make in moment decisions about societal, organizational and policy dilemmas. Breaking down this decision-making process and thinking about it more broadly, rather than individually, will be useful in giving direction to this training package. Involving support workers in this process is important as previous research suggests that they could have a role in service implementation and the development of policy as frontline workers; however, this has rarely been considered (Quilliam et al., 2017).

There are implications here for the organizations that employ those support workers, to develop new policies and provide support, guidance, time and access training to develop that knowledge.

## 5 | CONCLUSION

With the shift in focus to the Internet for all aspects of daily life, especially the shift in the developing and maintenance of personal and sexual relationships, access to the Internet is essential. Adults with intellectual disabilities are increasingly looking to access the Internet for these purposes, and for those who require support, how the support worker understands their role in doing so is an important factor in the outcome of what that support looks like. Findings from this study suggest that support workers believed adults with intellectual disabilities should have access to the Internet and develop personal and sexual relationships, however, they varied greatly in whether they felt it was part of their role to support that. Findings also highlighted a lack of training and guidance for support workers in how to deliver such support. At the heart of how support workers understand their role appears to be societal and organizational dilemmas about sexuality for people with intellectual disabilities, this informed how they make decisions, often regarding risk versus safety, for the person, they are supporting.

If support workers are often seen as “keyholders” by adults with intellectual disabilities, as other research suggests, then how they understand their role now and, in the future, will heavily impact on how those who need their support access the Internet for personal and sexual relationships. What is clear is that additional support, training and guidance is desired by those support workers. Robust training and guidance packages or programmes for support workers need to be created and should be a priority for professionals and organizations that employ support workers who work with adults with intellectual disabilities.

## ACKNOWLEDGMENTS

The authors acknowledge Dr Peter Oakes (Staffordshire University, R206 Science Centre, College Road, Stoke-on-Trent, ST4 2DE) and Dr Nicholas Todd (Staffordshire University, R206 Science Centre, College Road, Stoke-on-Trent, ST4 2DE) for their contribution.

## ORCID

Jason Lines  <https://orcid.org/0000-0002-7273-9328>

Helen Combes  <https://orcid.org/0000-0002-4487-037X>

## REFERENCES

- Azzopardi-Lane, C., & Callus, A. M. (2015). Constructing sexual identities: People with intellectual disability talking about sexuality. *British Journal of Learning Disabilities*, 43(1), 32–37. <https://doi.org/10.1111/bl.12083>
- Batey, G., & Waine, H. (2015). Safe internet access for service users. *Learning Disability Practice*, 18(3), 16–20. <https://doi.org/10.7748/ldp.18.3.16.e1613>
- Belton, P. (2018). *Love and dating after the Tinder revolution*. Retrieved from <https://www.bbc.co.uk/news/business-42988025>
- Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. Sage.
- Care Quality Commission (2015). *Housing with care: Guidance on regulated activities for providers of supported living and extra care housing*. Retrieved from [https://www.cqc.org.uk/sites/default/files/20151023\\_provider\\_guidance-housing\\_with\\_care.pdf](https://www.cqc.org.uk/sites/default/files/20151023_provider_guidance-housing_with_care.pdf)
- Care Quality Commission (2019). *Relationships and sexuality in adult social care services*. Retrieved from <https://www.cqc.org.uk/sites/default/files/20190221-Relationships-and-sexuality-in-social-care-PUBLICATION.pdf>
- Chadwick, D., Wesson, C., & Fullwood, C. (2013). Internet access by people with intellectual disabilities: Inequalities and opportunities. *Future Internet*, 5(3), 376–397. <https://doi.org/10.3390/fi5030376>
- Darragh, J. (2019). *Relationships in cyberspace: Experiences of adults living with intellectual disability, accessing internet-based social media to explore sexuality and develop relationships*. Doctoral dissertation, Flinders University, College of Nursing and Health Sciences.
- Darragh, J., Reynolds, L. C., Ellison, C., & Bellon, M. L. (2017). Let's talk about sex: How people with intellectual disability in Australia engage with online social media and intimate relationships. *Cyberpsychology: Journal of Psychosocial Research on Cyberspace*, 11(1). <https://doi.org/10.5817/CP2017-1-9>
- Department of Digital, Culture, Media & Sport (2017). *Policy paper – 2. Digital skills and inclusion – Giving everyone access to the digital skills they need*. Retrieved from <https://www.gov.uk/government/publications/uk-digital-strategy/2-digital-skills-and-inclusion-giving-everyone-access-to-the-digital-skills-they-need>
- Dobrinsky, K., & Hargittai, E. (2006). The disability divide in Internet access and use. *Information, Communication & Society*, 9(3), 313–334. <https://doi.org/10.1080/13691180600751298>
- Dunn, M. C., Clare, I. C. H., & Holland, A. J. (2010). Living 'a life like ours': Support workers' accounts of substitute decision-making in residential care homes for adults with intellectual disabilities. *Journal of Intellectual Disability Research*, 54(2), 144–160. <https://doi.org/10.1111/j.1365-2788.2009.01228.x>
- Elo, S., Kääriäinen, M., Kanste, O., Pölkki, T., Utriainen, K., & Kyngäs, H. (2014). Qualitative content analysis: A focus on trustworthiness. *SAGE Open*, 4(1), <https://doi.org/10.1177/2158244014522633>
- English, R. (2019). *Mental capacity for handling the internet: Court of Protection*. UK Human Rights Blog. Retrieved from <https://ukhumanrightsblog.com/2019/02/27/mental-capacity-for-handling-the-internet-court-of-protection/>
- Evans, A., & Rodgers, M. E. (2000). Protection for whom? The right to a sexual or intimate relationship. *Journal of Learning Disabilities*, 4(3), 237–245. <https://doi.org/10.1177/146900470000400306>
- Gergen, K. J. (1985). The social constructionist movement in modern psychology. *American Psychologist*, 40, 266–275. <https://doi.org/10.1037/0003-066X.40.3.266>
- Grieve, A., McLaren, S., Lindsay, W., & Culling, E. (2009). Staff attitudes towards the sexuality of people with learning disabilities: A comparison of different professional groups and residential facilities. *British Journal of Learning Disabilities*, 37(1), 76–84. <https://doi.org/10.1111/j.1468-3156.2008.00528.x>
- Hollomotz, A., & Speakup Committee. (2009). 'May we please have sex tonight?'—people with learning difficulties pursuing privacy in residential group settings. *British Journal of Learning Disabilities*, 37(2), 91–97. <https://doi.org/10.1111/j.1468-3156.2008.00512.x>
- Holmes, K. M., & O'Loughlin, N. (2014). The experiences of people with learning disabilities on social networking sites. *British Journal of Learning Disabilities*, 42(1), 1–5. <https://doi.org/10.1111/bl.12001>
- Lesseliers, J. (1999). *Right to sexuality?* *British Journal of Learning Disabilities*, 27(4), 137–140. <https://doi.org/10.1111/j.1468-3156.1999.tb00147.x>
- Lowe, K., Jones, E., Allen, D., Davies, D., James, W., Doyle, T., Andrew, J., Kaye, N., Jones, S., Brophy, S., & Moore, K. (2007). Staff training in positive behaviour support: Impact on attitudes and knowledge. *Journal of Applied Research in Intellectual Disabilities*, 20(1), 30–40. <https://doi.org/10.1111/j.1468-3148.2006.00337.x>
- Manthorpe, J., Samsi, K., Heath, H., & Charles, N. (2011). 'Early days': Knowledge and use of the Mental Capacity Act 2005 by care home managers and staff. *Dementia*, 10(3), 283–298. <https://doi.org/10.1177/1471301211403970>
- Mason, P., Timms, K., Hayburn, T., & Watters, C. (2013). How do people described as having a learning disability make sense of friendship? *Journal of Applied Research in Intellectual Disabilities*, 26(2), 108–118. <https://doi.org/10.1111/jar.12001>
- Mencap (2020). Retrieved from <https://www.mencap.org.uk/get-involved/working-us/support-worker-roles-mencap>
- Office for National Statistics (2018). *Internet access – households and individuals, Great Britain – Office for National Statistics: 2018*. Retrieved from <https://www.ons.gov.uk/peoplepopulationandcommunity/householdcharacteristics/homeinternetandsocialmediausage/bulletins/internetaccesshouseholdsandindividuals/2018>
- Oyedemi, T. (2015). Internet access as citizen's right? Citizenship in the digital age. *Citizenship Studies*, 19(3–4), 450–464. <https://doi.org/10.1080/13621025.2014.970441>
- Quilliam, C., Bigby, C., & Douglas, J. (2017). Being a valuable contributor on the frontline: The self-perception of staff in group homes for people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 31(3), 395–404. <https://doi.org/10.1111/jar.12418>
- Sallafranque-St-Louis, F., & Normand, C. L. (2017). From solitude to solicitation: How people with intellectual disability or autism spectrum disorder use the internet. *Cyberpsychology: Journal of Psychosocial Research on Cyberspace*, 11(1), <https://doi.org/10.5817/CP2017-1-7>
- Saxe, A., & Flanagan, T. (2014). Factors that impact support workers' perceptions of the sexuality of adults with developmental disabilities: A quantitative analysis. *Sexuality and Disability*, 32(1), 45–63. <https://doi.org/10.1007/s11195-013-9314-8>
- The Mental Capacity Act 2005 (2005). Retrieved from <http://www.legislation.gov.uk/ukpga/2005/9>
- Tufford, L., & Newman, P. (2012). Bracketing in qualitative research. *Qualitative Social Work*, 11(1), 80–96. <https://doi.org/10.1177/1473325010368316>

- Wilson, N., Meininger, H., & Charnock, D. (2009). The agony and the inspiration: Professionals' accounts of working with people with learning disabilities. *Mental Health Review Journal*, 14(2), 4–13. <https://doi.org/10.1108/13619322200900008>
- Windley, D., & Chapman, M. (2010). Support workers within learning/intellectual disability services perception of their role, training and support needs. *British Journal of Learning Disabilities*, 38(4), 310–318. <https://doi.org/10.1111/j.1468-3156.2010.00610.x>

**How to cite this article:** Lines J, Combes H, Richards R. Exploring how support workers understand their role in supporting adults with intellectual disabilities to access the Internet for intimate relationships. *J Appl Res Intellect Disabil*. 2021;34:556–566. <https://doi.org/10.1111/jar.12822>

## APPENDIX 1

### SEMI-STRUCTURED INTERVIEW SCHEDULE

This study investigates how support workers, in communal and supported living accommodation for adults with intellectual disabilities, understand their role in facilitating access to the Internet in the pursuit of intimate relationships.

- Could you tell me about how you understand your role, in general, as a support worker?
  - a. What expectations are there for how you support people within your role?
  - b. What about in terms of supporting people with their personal and sexual relationships?
  - c. Accessing the Internet is becoming part of everyday life for people; how do you understand your role in supporting people to access the Internet?
    - i. Are there any barriers to supporting people to access the Internet that you encounter?
    - ii. How does it feel talking about this?
- How would you go about supporting an individual to access the Internet for personal relationships—such as friendship building and maintaining those friendships, through avenues such as emails or using social media, like Facebook?
- How would you go about supporting an individual to access the Internet for sexual relationships? Through avenues such as dating apps or dating websites?
  - a. Have you given this support before?
  - b. Did you feel it was part of your role?
  - c. How did it go?
  - d. What difficulties might you/did you face when trying to support people to access these websites/apps?
  - e. What feelings does this conversation evoke within you?
- How would you go about speaking to a family member who asked about their son/daughters use of the Internet for these purposes?
  - a. What if the individual did not wish for their family member to know?
- If you felt there were some specific difficulties or risks, how would you go about addressing them?
- Do you feel you have enough training or knowledge about this to facilitate such access?
  - a. Does your organization offer training, guidelines or support for this?
- Do you think it would be more difficult supporting an individual to access the Internet for sexual relationships, rather than personal relationships?
  - a. Could you tell me more about that?
- Do you think there would be any differences in how you would support a male to access these things, compared to a female?
- Could you tell me more about that?/Elaborate