

“The Support Continuum”

Exploring how support workers understand their role in supporting adults with learning disabilities to use the internet for personal and sexual relationships

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Contents

Thesis Abstract	8
Paper 1: Literature Review	9
What factors influence how adults with intellectual disabilities access and use the internet?	9
Abstract	10
Introduction	11
The Internet	11
Benefits of Internet Access	11
Difficulties Arising from Internet Use	11
Digital Divide	12
People with Intellectual Disabilities and Inclusion, Exclusion and Loneliness	12
Rationale for this Review	13
Question	13
Method	13
Search Strategy	13
Inclusion criteria	14
Exclusion Criteria	14
Study Selection	14
Critical Appraisal Tool	17
Results	17
Study Characteristics	17
Sample	17
Inclusion/Exclusion Criteria	18
Quantitative Methods	19
Questionnaires	19

Other measures.....	20
Qualitative Methods.....	21
Interviews	21
Main Findings	22
Considerations and Quality Analysis	23
Themes	26
Risk and Benefits	26
The Role of Support	27
Training	28
Purpose	29
Skills and Equipment.....	30
Discussion	30
Future research and Clinical Implications.....	31
Critique of Review	33
Conclusion	34
References	35
Paper 2: Empirical Paper	42
How do support workers, supporting adults with learning disabilities, understand their role in facilitating access to the internet, for the purposes of personal and sexual relationships?	42
Abstract	43
Introduction	44
Aim of this study	46
Method	46
Researcher.....	46
Design	47
Procedure.....	48
<i>Participants - Recruitment</i>	48

Data Analysis	49
Ethics.....	50
Results	51
Social and Organisational Dilemmas.....	52
Policy Dilemmas.....	58
Power and Position	60
Discussion	61
Future Research.....	64
Strengths and Limitations	64
Clinical Implications	65
Conclusion	66
References	68
Paper 3: Executive Summary	74
Research Summary	75
Background	77
Method	78
Findings	78
Conclusion	82
References & Supporting Information	85
Appendix	87
Appendix A. Critical Appraisal Tool for Quantitative Papers	87
Appendix B. Critical Appraisal Scoring Table	88
Appendix C. Data Extraction Table	90
Appendix D. Submission guidelines for the Journal of Applied Research in Intellectual Disabilities	97
Appendix E. Semi-Structured Interview	104
Appendix F. Focus Group Organisational Sourcing Letter	106

Appendix G. Focus Group Participant Information Sheet	108
Appendix H. Focus Group Consent Form	111
Appendix I. Sourcing Organisations for Support Workers to Interview	113
Appendix J. Support Worker Interviews Participant Information Sheet	114
Appendix K. Interview Consent Forms	119
Appendix L. Interview Participant Demographic Forms	121
Appendix M. Interview Debrief Forms.....	122
Appendix N. Outcomes from Focus Group	123
Appendix O. Ethical Approval	125
Appendix P. Reflective Statement.....	126
Appendix Q. Thematic Analysis Process	127

Thesis Abstract

With internet use prominent in daily life, research investigating how adults with learning disabilities are accessing and using the internet is increasingly relevant. Three papers are presented in this thesis which aimed to provide additional understanding about this research topic.

The first paper outlines a review of the literature regarding what factors influence how adults with intellectual disabilities access and use the internet. The existing literature suggests a shift in the technology used to access the internet, from computers to smartphones. It also shows a shift in the purpose of internet use, from only using the internet for emails, to multi-platform usage, mainly social media. Significantly, it highlighted how important it is for some adults with learning disabilities to have access to support to assist with using the internet; in addition, the perceptions of those supporting impacted on how much support a person would receive.

The second paper details the empirical research that was undertaken in response to findings from the literature review. Eight support workers took part in this qualitative study which looked at how support workers understand their role supporting adults with learning disabilities to use the internet for personal and sexual relationships. Interviews were transcribed and analysed using thematic analysis. The themes of 'Social and Organisational dilemmas' with subthemes '*Role and Moral positioning*', '*Expectations of Support*' and '*Protected and Reflective space*'; 'Policy dilemmas' and 'Power and position' were found and discussed. This research highlighted the current gap in training and guidance available for support workers regarding supporting people to use the internet for personal and sexual relationships – suggesting more must be done to develop these training opportunities.

The final paper is an executive summary which condenses the empirical research and presents it in a format accessible to adults with learning disabilities, support workers, and organisations employing support workers.

Paper 1: Literature Review

What factors influence how adults with intellectual disabilities access and use the internet?

Word Count: 7,190

This literature review has been prepared with the intention of publication in the Journal of Applied Research in Intellectual Disabilities. Further editing and modifications will be made before submitting to the journal. Guidelines for publication in this journal can be found in Appendix D.

Abstract

Objective

The aim of this literature review was to examine and summarise research that investigated the factors which influence how adults with intellectual disabilities access and use the internet.

Method

During April 2018; MEDLINE, CINAHL, PsycARTICLES, PsycBOOKS, PsycINFO using EBSCOhost, Cochrane library and Web of Science (all databases) were searched. Further searching was completed by hand, using the references of those studies already identified and using Google Scholar.

Results

Nine papers were identified and are included in the review. Of those nine papers, two used qualitative methods, six used quantitative methods and a final paper used a mixed methods approach. Findings were presented through themes; Risk and benefits of internet access and use, the role of caregivers in supporting individual with intellectual disabilities to access and use the internet, the importance of training, what people with intellectual disabilities use the internet for, and data on the skills and equipment which people with intellectual disabilities are using.

Conclusions

The findings suggest that the number of people with intellectual disabilities accessing and using the internet has increased greatly over the last ten years, with use shifting away from desktop computers to smart phones. Findings also suggest that support staff and carers believe more training should be offered not only to themselves, but also the people they support, to use the internet effectively and safely. Future research looking at the impact of greater training opportunities, and the role of caregivers and support staff, particularly qualitatively is needed.

Introduction

The Internet

The Office for National Statistics (2018) in the UK, states that 99% of adults between 16-44 and 96.8% of adults between 45-54 are using the internet regularly. The internet has become an integral part of people's lives. Some of the more well-known uses of the internet include social media, online shopping and searching for information. But there are also developing areas of the internet, including online education, employment from home through remote interfaces, instant language translation tools; as well as considering the wider societal impact of online news and so called 'fake-news' (Allcott & Gentzkow, 2017). It is unsurprising then that internet access is being discussed as to whether it should be recognised as a basic right for all (Oyedemi, 2014).

Benefits of Internet Access

There is a growing research base of evidence which highlights the potential benefits of internet access and use. Some researchers highlight how the internet can be used to promote greater social equality and empowerment for those in the margins of society (Mehra, Merkel & Bishop, 2004). Others highlight the potential health and wellbeing benefits of internet access, for example with enhanced socialising and a greater sense of connectedness (Gatto & Tak, 2008). But also for therapeutic interventions such as Cognitive Behavioural Therapy delivered through online platforms, which have been shown in some cases to be as effective as clinic-based practice (Ruwaard et al., 2012).

Difficulties Arising from Internet Use

Perhaps somewhat surprisingly, using the internet to increase social opportunities and connect with others through social media platforms, has also been linked to an increase in the levels of loneliness (Morahan-Martin & Schumacher, 2003; Whitty & McLaughlin, 2007). Other difficulties have been highlighted, such as internet addiction (Kuss, 2016), and a range of issues for adolescents including poor sleep, anxiety, depression and low self-esteem (Woods & Scott, 2016).

Digital Divide

Those who have access to the internet can tap into the benefits mentioned, however, there are many people who have limited or no internet access, these groups of people include those with disabilities (Dobrasky & Hargittai, 2006), older adults (Gatto & Tak, 2008) and those in poorer countries without internet infrastructure (Norris, 2000). This idea of groups with internet access and groups without is sometimes referred to as the 'digital divide' (Williams, 2001).

People with Intellectual Disabilities and Inclusion, Exclusion and Loneliness
Efforts have been made through policies and initiatives to increase inclusion in society for marginalised groups, such as those with intellectual disabilities in the Valuing People document (Department of Health, 2009), including internet access (Department for Digital, Culture, Media & Sport, 2017). Public Health England (2015b) recognises the impact of social isolation and loneliness on physical and psychological wellbeing and have released guidelines on reducing social isolation across the lifespan (2015a). The World Health Organisation (Mathieson et al., 2008) also suggest links between social exclusion and mental health difficulties. Although the wider impact of loneliness and isolation has been noted for many years by researchers such as Caccioppo (2015), loneliness is often cited as a significant difficulty for people with intellectual disabilities in particular (Mason et al., 2013). Some research suggests that up to half of all adults with intellectual disabilities are chronically lonely, for example Gilmore and Cuskelly (2014), whom also attempted to build a model to help explain why this may be.

Considering the research which has highlighted the potential benefits of internet use and social networking, and the impact of isolation and high levels of loneliness within the adult intellectual disability population; promoting greater inclusion in the internet for those individuals would appear to be positive and worthwhile.

Rationale for this Review

Although the benefits of internet access have been highlighted, and the potential mental health benefits for people with intellectual disabilities touched upon, one area which is worth further investigation is how people with intellectual disabilities access and use the internet currently. Access to the internet ultimately supersedes the use of specific internet based tools, such as social media; therefore, investigating the factors which influence how adults with intellectual disabilities access the internet will be an important starting position before one can examine the uses of specific internet tools. A broad look at some of the research in this field suggested there is a growing research base looking at the use of social media and its impact, however, there appeared to be a limited amount of research which focused on how adults with intellectual disabilities access and use the internet more broadly.

Question

What factors influence how adults with intellectual disabilities access and use the internet?

Method

Papers were generated from a systematised literature search using a specific search strategy and selection process. Using inclusion and exclusion criteria, a set of papers were chosen and critically appraised using two appraisal tools. A narrative synthesis of the findings outlined in the papers generated themes which relate back to the research question.

Search Strategy

The following search terms were used (“learning disabilit*” OR “intellectual disabilit*” OR “developmental disabilit*” OR “mental retardation” OR “learning difficult*” OR “special needs”) AND (internet OR web OR website) AND (access OR use).

These databases were searched during April 2018; MEDLINE, CINAHL, PsycARTICLES, PsycBOOKS, PsycINFO using EBSCOhost, Cochrane library and Web of Science (all databases). Further searching was completed by hand using the references of those studies already identified and using Google Scholar, one further paper was identified.

Inclusion criteria

- 1) Published in English, due to lack of translation resources.
- 2) Adults at time of participation.
- 3) Study is conducted with adults with intellectual disabilities as the central focus.
- 4) Study is focused on access and use of the internet more broadly, rather than specific elements of the internet, such as Social Media.

Exclusion Criteria

- 1) Studies involving children as this review will focus on adults specifically. There are separate guidelines for children's access to the internet (UK Council for Internet Safety, 2018) which are beyond the scope of this review.
- 2) Papers with a specific focus on Autism Spectrum Disorders (ASD), or intellectual disabilities and Autism, will be excluded. Although some services are commissioned to cover both, there is a wealth of research which looks at the distinctions between the two, for example Bertelli *et al* (2015). This review will focus on intellectual disabilities only.

Study Selection

The selection process for papers was staged in the following way; firstly, papers were screened and filtered by title, then abstract, then after reading the whole paper. If deciding based on abstract was too difficult or unclear, the paper was read in full (See Figure 1).

In total, across all the databases, the search terms produced 891 results with limiters of peer reviewed and adults selected. 14 duplicates were removed, leaving 877 papers. Screening via title and then abstract removed 850, leaving 27 papers. The final 27 papers were obtained and read in full text, 19 of those papers were excluded due to the following; social media focus only (N=3), a review or commentary piece and not a study (N=4), focus on individuals not using the internet (N=1), focus on ICT equipment use rather than internet access (N=4), focus on ASD rather than intellectual disabilities (N=1), evaluation of training programme or specific website (N=2), focus on

internet bullying or danger (N=2), focused on access to educational material (N=1). Leaving 8 papers which fit the inclusion criteria.

Hand searching by looking at references in the sourced papers, revealed a further paper, this search strategy yielded 9 papers for review.

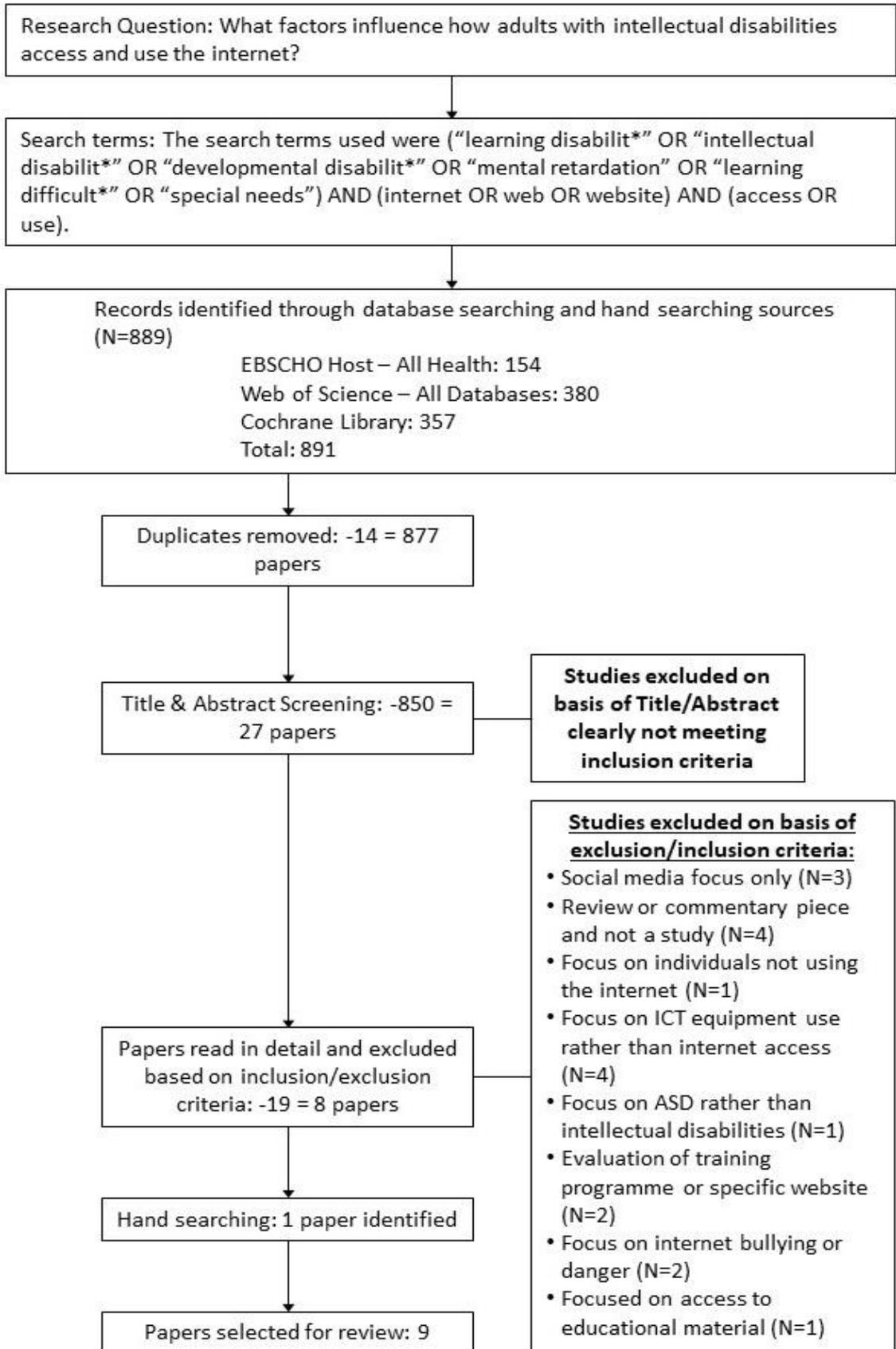


Figure 1. Literature Search process flow chart

Critical Appraisal Tool

Two critical appraisal tools were used to evaluate sourced papers. For qualitative papers, the Qualitative Critical Appraisal Skills Programme (CASP) tool (2018) was used. For quantitative papers, a critical appraisal checklist was developed (Appendix A) which included questions from pertinent sources; Downs and Black's (1998) appraisal checklist, the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement (2017) and the NICE Quality Appraisal Checklist – Quantitative Intervention Studies (2012). For mixed methods papers, the quantitative and qualitative elements were appraised separately using the appropriate appraisal tool. Appendix B shows the Quality Appraisal Table completed. Appendix C shows the Data Extraction Table and a quality score, derived from the Quality Appraisal Table, added to it.

Results

Study Characteristics

The review consisted of two papers using qualitative methods, six papers using quantitative methods and a final paper using a mixed methods approach. Studies were mainly from western countries, including two from the US, two from Spain, two from the UK, one from Canada, one from Sweden, however, there was one paper from Hong Kong. All the papers were cross-sectional in design (Carey et al., 2005; Chadwick et al., 2017; Chiner et al., 2017a; Chiner et al., 2017b; Hegarty & Aspinall, 2006; Li-Tsang et al., 2005; Lofgren-Mortenson et al., 2015; Lough and Fisher, 2016; Sallafranque & Normand, 2017). All studies reported the research aims or hypothesis. Appendix C also shows a summary of each study included in this review.

Sample

Lofgren-Martenson et al., (2015) qualitative paper used 13 adult participants; 8 professionals (active teachers) and 5 parents (of students attending the school) via strategic sampling. Participants were recruited from a specialist school for young adults (18-20) with intellectual disabilities. Hegarty and Aspinall's (2006) qualitative paper used day services and homes run by the

Home Farm Trust organisation in England, with the potential to access up to 750 adults with intellectual disabilities should they agree.

The quantitative papers used sample sizes ranging from 44 to 350, including adults with intellectual disabilities, parents of adults with intellectual disabilities, carers/support workers and the general population. Participants were recruited from a range of different settings, including a residential summer camp for adults with Williams Syndrome (Lough and Fisher, 2016), an organisation which provides support for people with intellectual disabilities (Chiner et al., 2017a; Li-Tsang et al., 2005), a sheltered vocational training programme for adults with intellectual disabilities (Chiner et al., 2017b), from advertisements circulated via email distribution lists, online forums and public noticeboards (Chadwick et al., 2016), and through mailed invitations to disability organisations and professionals serving people with disabilities in a specific geographical area (Carey et al., 2005).

Sallafranque and Normand's (2017) mixed method study used 8 adults (5 with intellectual disabilities and 3 with ASD) who were recruited by support staff from a regional rehabilitation centre designed for individuals with intellectual disability and autism spectrum disorders.

All of the papers identified used appropriate samples to address the aims of each study, broadly meeting the quality standards for sampling.

Inclusion/Exclusion Criteria

Inclusion and exclusion criteria varied across the papers, from clear to unstated. Hegarty and Aspinall (2006) inclusion criteria were adult service users of an organisation providing support for individuals with intellectual disabilities; exclusion criteria were less clear, however, they excluded one specific day service who supported adults with severe to profound disabilities, where computers would not be used. Sallafranque and Normand (2017) inclusion criteria to complete the questionnaire, were that the participant be over 18 years old, use the internet at least once a week and be able to understand and answer questions read to them from a questionnaire.

To be interviewed, the participants also needed to communicate well enough verbally to be understood.

Carey et al (2005) included individuals who were identified as having 'mental retardation' by state organisations or professionals, were capable of communicating answers to simple, closed-ended questions about their experiences with and attitudes related to technology, were 18 years of age or older and lived in Pennsylvania. Li-Tsang et al (2005) included participants who were adults aged 16 and above, were diagnosed as having mild, moderate or severe intellectual disabilities; exclusion criteria included participants with severe behavioural problems, poor comprehensive abilities or poor physical dysfunction.

The inclusion and exclusion criteria for the following papers was unclear or not stated (Lofgren-Martenson et al., 2015; Chadwick et al., 2017; Chiner et al., 2017a; Chiner et al., 2017b; Lough and Fisher 2016). This may have implications for assessing reliability, replicability and bias in the results.

Quantitative Methods

Questionnaires

Most of the quantitative papers used modified versions of established questionnaires, adaptations were usually to ensure people with intellectual disabilities would be able to understand what is being asked; Chadwick et al (2016) used the risks and benefits checklist developed by Livingston and Haddon (2009), the risks ratings and separate benefits ratings scales were found to be internally reliable (Cronbach's alphas = 0.94 and 0.95 respectively). The two papers by Chiner et al. (2017a & 2017b) and the paper by Lough and Fisher (2016) also developed adapted versions of the European Network EU Kids Online (Livingston & Haddon, 2009) instrument.

In Chiner et al (2017a) two versions were produced, one for family members of adults with intellectual disabilities and one for professionals, it was assessed by a panel of experts (n=11) and had a content validity index of 1 for the family version and 0.98 for the professional's version. In Chiner et al

(2017b) three versions were produced, one for adults with intellectual disabilities, one for their family members and one for professionals, again it was sent to a panel of experts obtaining similar scores to the other paper. Information on the panel of experts is not described in Chiner et al (2017a), however, in Chiner et al (2017b) the panel is described as experts on ICT and intellectual disability from three different universities and a service organisation. Lough and Fisher's (2016) adaptations included visual aids, such as pictures of thumbs up/down, but provided no data on reliability or validity.

Sallafranque and Normand's (2017) mixed method approach used a questionnaire for the quantitative element, it used questions from the Youth Internet Safety Survey (Ybarra et al., 2007). However, no data was provided regarding reliability or validity.

Carey et al (2005) developed their own survey around a set of core topics, for example, a participants self-perceived ability related to technology use, they also used flash cards to assist people in remembering and understanding potential answers. However, it is not stated how they devised the questions or whether they drew upon other research to inform this, in addition, there is no data on the reliability nor validity of the survey.

Other measures

Lough and Fisher (2016) used the Kaufman Brief Intelligence Test, 2nd Edition (KBIT-2; Kaufman & Kaufman, 2004) to assess verbal, nonverbal and full-scale IQ. They also developed E-safety scenarios, which were influenced by the Test of Interpersonal Competence and Personal Vulnerability (Wilson et al., 1996). The E-safety scenarios were situations with three possible follow-up options, broadly moving from options with the lowest risk (e.g. say no to a request to meet someone on the internet), to answers with the highest risk (e.g. agreeing to meet a stranger from the internet) – the scales showed high reliability (Cronbach's alpha = 0.886).

Li-Tsang et al (2005) developed a computer competency checklist which looked at both use of the hardware (e.g. mouse and keyboard) and internet use, they state that standardised measures were not used because most of them look at motor skills rather than any cognitive abilities. Items on the checklist were reviewed by five professionals working for people with intellectual disability, an instruction manual was also created. The inter-rater reliability of the created instrument was high (intraclass correlation coefficient (3.1) = 0.98).

Qualitative Methods

Interviews

Lofgren-Mortenson et al (2015) used semi-structured interviews with a set of pre-designed questions around two main themes; the internet as an arena for love and sexuality, and the attitudes and behaviour of parents and professionals concerning the use of the internet by young people with intellectual disabilities. Interviews were conducted in focus groups for the professional participant group, and in pairs for the parent group (apart from one lady who interviewed alone due to partner illness). Interviews were conducted by the paper authors and held at either the university or at a local club for people with intellectual disabilities.

Sallafranque and Normand's (2017) mixed method approach used semi-structured interviews for the qualitative element, using a five-point topic guide to direct the questions; family, friends, self, love and sexual relationships, and navigating the web and touching on sexual cyber-solicitation. It is not explicitly stated who conducted the interviews, however, it states that the principal investigator arranged the interviews with the participant, and interviews took place wherever the participant preferred – usually at home, or one of the local rehabilitation centres.

Hegarty and Aspinall (2006) describe their study as a qualitative program evaluation, broadly it fits within the tradition of ethnography. The approach outlined is somewhat unclear, however, it appears that the researchers visited various services, all under the umbrella of one larger organisation,

which provide support to adults with intellectual disabilities and conducted ad-hoc interviews with individuals. There is no information regarding the structure or content of the interviews, however, the researchers did take pictures alongside the interviews.

Main Findings

Carey et al (2005) found that only a quarter of their sample of adults with intellectual disabilities was accessing the internet despite interest in using such technologies being much higher, notable barriers were a lack of access, lack of training and support, and expense. Chiner et al (2017a) found that caregivers perceived adults with intellectual disabilities as more vulnerable to risk online and rarely received training for strategies to prevent/lessen those risks; they believe organisations should be providing this training to promote inclusion of people with intellectual disabilities in the digital arena. Chiner et al (2017b) found that people with intellectual disabilities are increasingly using smartphones and the internet compared to previous research, they also highlighted a number of risks and undesirable behaviours people with intellectual disabilities had faced online, finally differences were found in the perceived benefit of internet access between adults with intellectual disabilities and their caregivers.

In a survey of the general public, Chadwick et al (2016) found that perceived risks and benefits of being online were greater for individuals with intellectual disabilities compared to those without, however, there appeared to be some misconceptions around how much support people with intellectual disabilities actually needed to access and use the internet. Lough and Fisher (2016) found that adults with Williams syndrome frequently used the internet and social media, and would interact with both known and unknown individuals online, however, they were also more likely to engage in socially risky behaviours compared to non-social, e.g. agreeing to meet a stranger met online.

In Li-Tsang et al's (2005) survey of adults with intellectual disabilities, only a small section of the sample knew how to access the internet; however,

younger people had better I.T. skills in general. They also found that training for people with intellectual disabilities to use the internet was limited, and some caregivers felt that their own understanding of using the internet and I.T. more broadly was inadequate. Through questionnaire and interview, Sallafranque and Normand (2017) found that adults with intellectual disabilities used the internet for communications, entertainment, and gaming, however, they all had some distressing experiences e.g. being insulted. They also found that individuals with intellectual disabilities relied on friends, parents or social workers to avoid/rectify cyber-victimisation.

Lofgren-Mortenson et al (2015) found that professionals and parents consider young people with intellectual disabilities more vulnerable than other youth when using the internet, parent's rated the risk of loneliness higher than the risk of being abused. They also found differences in professional's views versus parent's views, particularly around using the internet for sexual purposes, with both considering the risks and positive opportunities internet use can offer. Finally, Hegarty and Aspinall's (2006) qualitative programme evaluation found that access and use of ICT equipment and the internet by adults with intellectual disabilities (service users) varied from service to service, other factors included staff skill level, training and timetabling; in services where there was a dedicated member of staff who was interested and committed to promoting computer use, access levels were higher.

Considerations and Quality Analysis

The papers reviewed here are generally methodologically sound, although there are several issues which must be highlighted before conclusions are made.

The first consideration concerns the samples. None of the papers using quantitative methods included data on power calculations, which makes it difficult to critically appraise the sample sizes. However, some of the quantitative papers have used sample sizes which could be considered too small, although they do highlight this in the limitations section (Chiner et al., 2017a; Lough & Fisher, 2016). A number of samples had participants which

were either majority female (Chadwick et al., 2016; Lough & Fisher, 2016 (family members); Lofgren-Martenson et al., 2015) or male (Lough & Fisher, 2016 (individuals with Williams Syndrome)), this can be particularly important in studies such as these which are looking at people's perceptions, as one gender is under-represented.

Many of the papers used samples from one specific support organisation or group, involving either service users, their families and/or members of staff (Chiner et al., 2017a; Chiner et al., 2017b; Lough & Fisher, 2016). This further increases the difficulty in generalising the findings, as individual organisations will have different policies, for example, in regard to how they provide support, the structure of their services and recruitment processes. Another consideration is samples involving professionals and support staff members, some papers included staff members with years of experience ranging from one to twenty-eight (Chiner et al., 2017a; Chiner et al., 2017b) significant differences in experience are likely to be a factor in how they might view risk in particular. Another paper was unclear about how much experience their participant professionals or support staff had (Lofgren-Martenson et al, 2016).

One paper used a sample which included individuals with intellectual disabilities and individuals with an autism spectrum disorder without an intellectual disability (Sallafranque & Normand, 2017). However, results and discussions were not explicitly clear as to how participants responded, which is pertinent as there are clear differences in disabilities between individuals with intellectual disabilities and those with ASD, particularly regarding social skills (Smith and Matson, 2010). Finally, one paper was unable to provide any specific data about their participants at all (Hegarty & Aspinall, 2006) other than up-to 750 adults with intellectual disabilities.

Another area for consideration is the questionnaires and other measures used in the quantitative papers. Many of the papers used modified versions of other questionnaires (Chadwick et al., 2016; Chiner et al., 2017a; Chiner et al., 2017b; Lough & Fisher, 2016; Sallafranque & Normand, 2017) others

developed their own measures (Carey et al., 2005; Lough & Fisher, 2016; Li-Tsang et al., 2005). Data on validity and reliability was provided for some of the measures, however, there are some other broader difficulties with questionnaires and surveys such as; how useful it is modifying them for people with intellectual disabilities (Finlay and Lyons, 2001), that often only people with strong views will respond to them (McLeod, 2014) and it can be difficult to know who actually completed the forms (McLeod, 2014).

A further consideration is that of bias. Surprisingly, most of the papers did not outline any detail about the researchers (Chiner et al., 2017a; Chiner et al., 2017b; Sallafranque & Normand, 2017; Chadwick et al., 2016; Lough & Fisher, 2016; Carey et al., 2005; Li-Tsang et a., 2005). Although this is somewhat common for quantitative papers, this makes it difficult to evaluate the researcher's personal motivations and investments in the research.

The qualitative papers offered some detail on the researchers. One paper discussed the researchers in some depth (Lofgren-Martenson et al., 2015) and outlined the processes used to attempt to counteract the personal interpretations, for example, having transcribed materials and codes continuously reflected and discussed within the research group. Another paper had minor details about the researchers (Hegarty and Aspinall, 2006). However, bias was not discussed, despite several key considerations; one of the researchers had previously worked for the organisation which was to be evaluated, and that all draft reports were first shown to the organisations management to check for inaccuracies.

Finally, although some of the difficulties involving people with intellectual disabilities as co-producers of research have been highlighted by researchers such as Gilbert (2004), the benefits of co-production have been clearly outlined (Lorito *et al.*, 2017). None of the papers in this review were co-produced by people with intellectual disabilities.

Themes

With these considerations discussed, the broader findings of the papers in this review have been outlined in the in form of themes, generated using a narrative synthesis of the findings, relating back to the research question.

Risk and Benefits

The majority of the papers in this review had some degree of focus on the risks and benefits of adults with intellectual disability using the internet. Chiner et al (2017a) surveyed family and staff of adults with intellectual disabilities and 91% of them felt that the internet is not safe for adults with intellectual disabilities compared to just 34% for adults without intellectual disabilities. In Chiner et al (2017b) a significant proportion of their sample of adults with intellectual disabilities had experienced problems online such as being blocked from an activity, being threatened or insulted, receiving sexual photos unrequested and having someone use their passwords without their consent. Chiner et al (2017b) also found that caregivers reported that people with intellectual disabilities had engaged in undesirable behaviour when going online more often than the respondents themselves.

Chadwick et al's (2016) survey of the general population found the greatest perceived risks for adults with intellectual disabilities accessing the internet was being bullied, threatened or harassed online, proving too much personal information and being more susceptible to online scams. These risks were different from the self-reported risks of internet use for adults without an intellectual disability, which included exposure to inappropriate pornographic material, becoming addicted to social media and engaging in copyright infringement/illegal activity. Other risks are seen in an emotional way, Lofgren-Mortenson et al's (2015) interviews of professionals working with young people with intellectual disabilities suggests that the internet can also be seen as an arena for disappointment and conflict, specifically related to online dating. They also highlighted how young people with intellectual disabilities can sometimes be naïve when it comes to using the internet to explore their sexuality, not fully understanding the meanings of things that are written in text online, or understanding the consequences of writing things

with sexual connotations. Perhaps surprisingly, parents who were interviewed did not raise issues of risk as often as the professionals did.

Risks were looked at through the lens of internet safety in Lough and Fisher's (2016) study involving adults with Williams syndrome. Analysing e-safety scenarios, they found that the participants were significantly more likely to engage in risky situations which were social in nature, rather than non-social. In more detail, it was found that adults with Williams syndrome were significantly more likely to agree to arrange to meet an unknown person in real life compared to talking to an unknown person online or engage in a non-social risky online activity.

Benefits of internet use are also highlighted in a number of papers. Chadwick et al (2016) reported that the general population perceived the internet to be highly beneficial for adults with intellectual disabilities, particularly in regard to social and support related online activities. Other benefits highlighted were; opportunities to engage in social groups and access and use advice websites. Aspects perceived as least beneficial for people with intellectual disabilities was the possibility of saying things they would find difficult face-to-face using online methods instead, but also decision making, critical thinking and developing identity. Other benefits are also hinted at by professionals in Lofgren-Mortenson et al's (2015) paper, they emphasise the internet as an important arena for love and sexuality as young people with intellectual disabilities are often isolated in real life, or as a way to show that they are 'normal'. In the same study, parents also highlighted the benefits of the internet; however, it was more focused on positive social aspects, rather than specifically regarding sexuality.

The Role of Support

Although much of the research involving caregivers focused on risk and benefits, some of the papers focused on the perceptions of caregivers and differences between caregiver views and people with intellectual disabilities. In Chiner et al (2017a) there were some differences between the concerns of staff members compared to family members in the use of the internet for

adults with intellectual disabilities, although some of the concerns scored highly across both; that someone would use the persons personal information without their consent, being asked for photos or personal information, receiving unwanted sexual photos or videos, or being threatened. Furthermore, Chiner et al (2017a) reported that many of the strategies used by caregivers to prevent risks on the internet for people with intellectual disabilities were very much about talking to the person; talking to them about what they have done, talking about risks of online chatting and flirting with strangers, talking about risks of identity and data theft, talking about which web pages are appropriate and which are not. Less frequently used strategies were things such as installed programs to block certain websites, controlling the time spent online and checking online history.

In Hegarty and Aspinall's (2006) service evaluation, they found that individuals with intellectual disabilities were more likely to receive support to use the internet, for purposes such as emailing family, in supported living environments compared to day services - this was specifically related to staffing levels and therefore the capacity to offer 1:1 support time. They also found that caregivers were using the internet whilst at work to access information on medical syndromes. Some families in Li-Tsang et al's (2005) study prevented individuals with intellectual disabilities whom they were caring for from using computer systems due to the fear that they might damage the system.

The importance of having support to enable people with intellectual disabilities to access and use the internet is stressed in over half of the papers (Li-Tsang et al., 2005; Carey et al., 2005; Hegarty and Aspinall, 2006; Lofgren-Martenson et al., 2015; Lough and Fisher, 2016; Chadwick et al., 2016)

Training

Many of the papers mention training for adults with intellectual disabilities to use the internet, but also for caregivers not only in regard to supporting people to use the internet, but around risk and safety. Li-Tsang et al (2005)

found that training opportunities for caregivers, and caregiver knowledge of I.T. more broadly, were significant factors in the number of adults with intellectual disabilities successfully accessing I.T. and the internet – lack of systemic training for both caregivers and individuals with intellectual disabilities more broadly was also highlighted. Lack of training was also highlighted by support workers in Hegarty and Aspinall's (2006) service evaluation as a barrier to individuals with intellectual disabilities being supported to use computers and the internet. Chiner et al (2017a) found that only 43% of their sample of caregivers felt they were trained enough to prevent problems encountered by the people they are supporting. In fact, the majority of caregivers in their study received information about internet safety from the media, such as television, newspaper, and radio (55%). Almost all of the caregivers (96%) had not received training in their workplace, but most would prefer this to be where training is received (82%).

The importance of training for both adults with intellectual disabilities and their carer's in order to facilitate greater access and use of the internet is highlighted in many of the papers (Li-Tsang et al., 2006; Hegarty and Aspinall, 2006; Lofgren-Martenson et al., 2015; Lough and Fisher, 2016; Chiner et al., 2017a; Chiner et al., 2017b)

Purpose

What people with intellectual disabilities use the internet for is considered in several papers. Carey et al's (2005) sample of adults with intellectual disabilities used the internet for searching for travel and event information (65%), internet gaming (60%) and reading the news (55%). Hegarty and Aspinall (2006) found that adults with intellectual disabilities in the services they observed used the internet mainly for emailing family, finding out about holidays, timetables, special interest websites e.g. trains, and listening to music. In contrast to the findings of older papers, Chiner et al (2017b) showed that in their sample, people with intellectual disabilities highlighted multiple uses for the internet, with a high percentage using it for watching videos (77%), chatting with friends (70%), using social networks (66%), listening to music (84%), watching films (53%) and writing emails (46%).

Lough and Fisher's (2016) survey of adults with Williams syndrome and their parents found that the internet was mainly used for watching YouTube videos (100%) and social networking (85.2%), other uses included emails (59.3%), instant messaging (51.9%) and chatrooms (44.4%). Sallafranque and Normand's (2017) study found that adults with intellectual disabilities mainly used the internet for social networking, email, making friends and searching for information – other uses included dating sites, video streaming, three men reported using the internet for gaming and pornography also.

Skills and Equipment

Several papers touch on the equipment that adults with intellectual disabilities use to access the internet; older papers highlighted the use of electronic organisers and desktop computers as a way of accessing the internet (Carey et al., 2005). Li-Tsang et al (2005) found that nearly half of their sample of adults with intellectual disabilities did not have the skills to access the internet using a computer (42.8%), although the level of intellectual disability was a significant factor in score, those with more severe disabilities tended to have greater problems using I.T. equipment more generally. Several papers found that younger individuals with intellectual disabilities were much more likely to use technology and the internet (Carey et al., 2005; Li-Tsang et al., 2005). A lack of suitable equipment and software was highlighted by staff in one organisation as a barrier to individuals with intellectual disabilities accessing the computer and internet (Hegarty and Aspinall, 2006). In contrast, Chiner et al (2017b) found that in their sample, the majority of people with intellectual disabilities use smartphones to go online, compared to desktop computers and laptops. Similarly, Lough and Fisher (2016) found that in a group of adults with Williams syndrome, 96.3% of the sample used a smartphone to access the internet, compared to tablets (74.1%), laptop (55.6%), games console (40.7%) and a desktop computer (33.3%).

Discussion

This review looked at nine papers which fit the inclusion criteria for the research question - what factors influence how adults with intellectual disabilities access and use the internet? Findings from these papers were

broken into five main themes; risks and benefits, the role of support, training, purpose and skills and equipment. There was also a number of contrasts seen between research conducted around 2005 compared to more recent research 2015 onwards, such as; the number of people with intellectual disabilities accessing the internet has increased, equipment adults with intellectual disabilities use to access the internet has shifted very much away from desktop computers to smartphones, and what adults with intellectual disabilities actually use the internet for - with social media now accounting for a large percentage of usage, where previously it was non-existent.

Policy promoting greater inclusion for people with intellectual disabilities in society, and on the internet more specifically was highlighted in the introduction of this review in the Valuing People document (Department of Health, 2009), including internet access (Department for Digital, Culture, Media & Sport, 2017). The findings from the papers appear to provide some support for the initiatives driven by these policy changes – people with intellectual disabilities are using the internet in much greater numbers. In addition, the findings from the papers reviewed here show high levels of participation in social networking websites. Greater levels of participation in social networking websites could potentially help with the high levels of loneliness in the adult intellectual disability community, which were highlighted earlier in this review (Mason et al., 2013; Gilmore & Cuskelly, 2014). However, caution must be taken when suggesting that social networking websites are effective at reducing loneliness, as some research has shown that for some individuals, it has had the opposite effect (Morahan-Martin & Schumacher, 2003; Whitty & McLaughlin, 2007).

Future research and Clinical Implications

The papers reviewed highlight a number of key areas for future research. One of the most highlighted areas was for a focus on professionals and families, and how they support people with intellectual disabilities to use the internet (Chiner et al., 2017a; Chiner et al., 2017b; Chadwick et al., 2016; Lofgren-Martenson et al., 2015; Carey et al., 2005). Another area for future research to consider is training for people with intellectual disabilities to use

the internet (Chiner et al., 2017a; Chiner et al., 2017b; Sallafranque & Normand, 2017; Chadwick et al., 2016; Lough & Fisher, 2016; Hegarty & Aspinall, 2006; Li-Tsang et al., 2005) and also training for professionals and families to properly support people with intellectual disabilities to use the internet (Chiner et al., 2017a; Chadwick et al., 2016; Lough & Fisher, 2016; Hegarty & Aspinall, 2006).

Although there is an apparent thirst for greater training opportunities, caution must be taken when generating and delivering training packages. Training is often evaluated only at the surface level, with a focus on measuring trainee's initial reactions and feedback. Kirkpatrick and Craig's (1970) and Kirkpatrick's (1996) influential work on the evaluation of training material more broadly suggests there are four levels of evaluation, three of which go beyond that surface level. In the fourth level of evaluation, Kirkpatrick highlights the importance of measuring whether there was an actual improvement in the skills or qualities which were targeted for improvement by the training – whether the training delivered what it really set out to do. Further research and a greater depth of evaluation into training opportunities for both people with intellectual disabilities to access and use the internet, and the people supporting them, would be beneficial.

Clinical implications were highlighted by many of the reviewed papers. One paper highlighted that gauging perceptions and management of risk from people with intellectual disabilities and those providing support can inform practice and intervention (Chadwick et al., 2016). Several papers documented that the levels of perceived risk for adults with intellectual disabilities using the internet was higher than for those without intellectual disabilities (Chiner et al., 2017a; Chiner et al., 2017b; Chadwick et al., 2016; Lofgren-Martenson et al., 2015) or, using e-safety scenarios which suggested individuals with intellectual disabilities were more likely to take risks online (Lough & Fisher, 2016). Organisational approaches were highlighted in one paper as significant to improving adults with intellectual disabilities access to and use of the internet (Hegarty & Aspinall, 2006) as care and support staff

are often limited in their actions based on the policies and leadership structures of the wider organisations.

Clinicians working in specialist services for people with intellectual disabilities, run by health organisations such as the NHS, may be faced with an increasing number of difficulties related to internet use in the future. The risks and benefits of internet use have been touched upon by the papers in this review and increased internet access is likely to go hand-in-hand with increased levels of exposure to risk. Perhaps there is scope for community-based training interventions, developed and co-lead by people with intellectual disabilities, with clinicians from local community mental health teams offering input when required.

Critique of Review

This review included only peer reviewed articles which could lead to some publication bias. The review also only captured nine papers, which is limited in size, however, does also highlight that it is likely an area in need of further research. Additionally, only papers written in English were included in this study due to limited translation resources, papers written in other languages may provide additional data to improve the generalisability of the findings here.

The appraisal tools used and the reviewer's lack of experience conducting literature reviews must also be acknowledged. It is possible that the reviewer was at times overly critical or generous regarding the appraisal of the papers; also, it is possible that the reviewer included or excluded papers where a more experienced reviewer may have chosen differently. The appraisal tool for the quantitative papers was created by the reviewer using information from several already existing tools; again, a more experienced reviewer may have developed this differently. Efforts were made to reduce the impact of these issues on the review overall; by utilising supervision with the academic supervisor at the University and by making use of peer revision and supervision groups.

Finally, the reviewer has worked clinically with adults with intellectual disabilities for several years and, inevitably, will have developed their own views on this topic. This may have influenced the critical appraisal of the papers and the direction of the review itself.

Conclusion

This review attempted to examine and critically appraise the literature available for the research question; what factors influence how adults with intellectual disabilities access and use the internet? Using the outlined search strategy, nine papers were chosen and reviewed. Findings were presented through themes; the risks and benefits of internet access for people with intellectual disabilities, the role of caregivers in supporting people with intellectual disabilities access and use the internet, the importance of training for both people with intellectual disabilities and their caregivers in accessing and using the internet, what people with intellectual disabilities use the internet for, and the skills and equipment people with intellectual disabilities have access to in regard to internet use. Although generally the nine papers were methodologically sound, some issues were outlined and must be taken into consideration when putting weight to the findings and recommendations. Areas for future research should include more qualitative research and look more closely at the role of caregivers in support people with intellectual disabilities to access and use the internet, and the development, delivery and impact of training for both people with intellectual disabilities and their caregivers in accessing and using the internet.

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Paper 2: Empirical Paper

How do support workers, supporting adults with learning disabilities, understand their role in facilitating access to the internet, for the purposes of personal and sexual relationships?

Word Count: 7463

This paper has been written in accordance with University requirements for thesis submission, with the intention of submission for publication in the *Journal of Applied Research in Intellectual Disabilities*. Author guidelines for manuscript submission can be found in Appendix D.

Key words: internet, learning disabilities, thematic analysis, relationships, support

Abstract

Background

Some adults with learning disabilities require support to access the internet. The aim of this study was to explore how support workers, providing support to adults with learning disabilities, understand their role facilitating internet access for the purposes of personal and sexual relationships.

Method

Eight support workers took part in this study. All participants were interviewed, one-to-one, using a semi-structured interview format. Thematic analysis was used to analyse interview data.

Results

Three main themes were identified; Social and Organisational Dilemmas (with subthemes of role and moral positioning, expectations of support, and protected and reflective space), Power and Position and Policy Dilemmas.

Conclusion

Support workers felt that adults with learning disabilities should have access to the internet for personal and sexual relationships. However, there was a continuum of views on whether they felt it was within their role to provide support to do this. A lack of training was also highlighted.

Introduction

Certain groups of people, such as those with disabilities are known to have difficulty accessing the internet (Dobransky & Hargittai, 2006), some Government departments have generated policy to promote greater inclusion for people with learning disabilities on the internet (Department of Health, 2009; Department for Digital, Culture, Media & Sport, 2017). It seems that adults with learning disabilities are increasingly looking to access the internet to engage in internet activities, however, access is often seen as risky for this population and research conducted has tended to focus on internet safety and risk prevention (Batey & Waine, 2015). Other legislation, such as the Mental Capacity Act (2005), was generated to ensure individuals, including some people with learning disabilities that lack the capacity to make decisions, have the right to support in making decisions. It was designed to be empowering and as least restrictive as possible and has been central to several legal cases involving adults with learning disabilities and internet use (English, 2019a; English, 2019b). The office of National Statistics (2018) state that we are placing more emphasis on the digital world for many activities: from paying bills, online shopping, job applications to maintaining personal relationships through social media and dating sites. Whilst legislation such as the Human Rights Act (1998) covers areas such as a right to life, or the right to marry it does not yet explicitly cover internet access, however arguably internet access should be a basic human right (Oyedemi, 2015).

There are challenges for support workers to enable safe access to the internet whilst negotiating the risks, maintaining privacy and making judgements about what is appropriate and inappropriate for adults with learning disabilities (Chadwick, Wesson & Fullwood, 2013). This is made more difficult because organisations providing supported living accommodation to adults with learning disabilities often outline policies and procedures which are risk averse and do not provide adequate training around internet use (Windley & Chapman, 2010). Some adults with learning disabilities view their support workers as the 'key holder' to activities (Mason et al., 2012), which emphasises the role support workers have regarding

access to and use of the internet for the people they support. Key holding is a powerful concept, not only in terms of physical needs such as assistance with personal care, but also wider themes of access to the community (Bigby & Wiesel, 2014), building and maintaining friendships, and accessing the internet (Seale, 2014).

Using the internet to access social media websites, such as Facebook and apps such as Tinder, to develop personal and sexual relationships, has become more prominent than ever before (Belton, 2018). Although, for people with learning disabilities, using social media such as Facebook can often be a negative experience (Holmes & O'Loughlin, 2012). Hollomotz and The Speakup Committee (2008) also highlighted the difficulties people with learning difficulties can face when seeking private space to explore sexual relationships, particularly for those living in communal accommodation. There are further challenges for people with learning disabilities who are looking to engage in sexual relationships, which include issues around capacity and the law (Murphy, 2003; Evans & Rogers, 2000; Hall & Yacoub, 2008), the impact of social and cultural norms ascribed to people with learning disabilities versus the perceptions of their own sexuality (Azzopardi-Lane & Callus, 2015), and other structural and organisational problems in allowing relationships between service users (Lesseliers, 1999).

For those adults with learning disabilities requiring support to use the internet to develop personal and sexual relationships, the views and attitudes of their support workers may be significant, particularly if they are seen as holding the 'key' (Mason et al., 2012). Research has investigated how attitudes of support workers impacted upon the provision of support to those adults with learning disabilities looking to explore sexual and personal relationships (Hamilton, 2008; Saxe & Flanagan, 2013), as well as the attitudes and willingness of support workers to support adults with learning disabilities regarding their sexuality (Andrea, 2011). Further research has looked at support worker attitudes towards sexuality in the learning disability population more broadly (Grieve et al., 2009) and thoughts on how best to support adults with learning disabilities to develop sexual and romantic relationships (Harflett & Turner, 2016). There are other factors which impact on how those

who support people with learning disabilities facilitate their support such as the regular ethical and moral dilemmas they face (Wilson, Meininger & Charnock, 2009), others highlighted how the law influences their decision-making processes (Dunn, Clare & Holland, 2010).

Although there is a growing research base investigating the views and attitudes of support staff regarding sexuality and personal relationships for adults with learning disabilities, there is little research looking at how support workers understand their role in facilitating access to the internet for such purposes. If support workers are often seen as 'key holders' by those adults with learning disabilities whom they are supporting, then they are important in facilitating successful access to the internet for the purposes of developing and maintaining sexual and personal relationships. As we place more emphasis on the digital world, many adults with a learning disability want to be included in that, but if they require support to do this, learning how their support workers understand their role in doing this could have a significant impact on what that support looks like.

Aim of this study

This study aimed to investigate how support workers, supporting adults with learning disabilities, understand their role in facilitating access to the internet, for the purposes of personal and sexual relationships.

Method

Researcher

The researcher is a third year Trainee Clinical Psychologist who has worked in various roles with people with learning disabilities. The researcher took a social constructionist epistemological position and sees views and beliefs as being socially constructed through interactions with others and the world, rather than created individually. Further information about the researcher can be found in a reflective statement (Appendix P).

Consultation

The researcher worked with a focus group of experts-by-experience, adults with learning disabilities who are currently receiving support to use the internet for personal and sexual relationships, to help generate the semi-

structured interview schedule. In the focus group, six adults with learning disabilities and two support workers took part, demographic data was not collected for this.

Three organisations that provide community-based support to adults with learning disabilities in Staffordshire and Shropshire, England, were found online and approached via email to arrange a focus group regarding the research topic (Appendix F). One organisation showed an interest and the focus group participant information sheet (Appendix G) and consent forms (Appendix H) were sent to them, then dates were arranged to undertake the focus group. The organisation agreed to ask the service about the focus group and whether they would like to attend. The researcher began the discussion by outlining the planned research and the aims of the focus group which was to help shape the interview questions for the support workers regarding how they understand their role supporting adults with learning disabilities to access the internet for personal and sexual relationships. Focus group discussion was placed onto three whiteboard sheets (Appendix N). This information was used for when the researcher created the semi-structured interview questions (Appendix E). The researcher included additional questions about family and gender differences to the semi-structured interview schedule to represent some of the views expressed by the focus group. The researcher planned to visit the focus group upon completion of the research to disseminate the findings and gather additional views.

Design

This qualitative study used semi-structured interviews to guide discussion and encourage in-depth exploration of how support workers understand their role in supporting adults with learning disabilities to use the internet for personal and sexual relationships. This study offers an opportunity to capture rich data about how those support workers understand their role, which may have been more difficult to truly capture with quantitative methodology.

Data collected from interviews were transcribed and analysed using thematic analysis to identify themes and patterns across the data set. The structured

approach to thematic analysis, outlined by Braun and Clarke (2006; 2013) was utilised. Thematic analysis was chosen, rather than other forms of qualitative methods, due to its flexibility and accessibility, particularly regarding making sense of collective meaning and understanding across a data set. This contrasts with methods such as interpretative phenomenological analysis (IPA), which look more closely at individual experiences.

Procedure

Participants - Recruitment

Eight organisations across Staffordshire and Shropshire, providing support services to adults with learning disabilities were found online and invited to participate in the study (Appendix I). There were challenges recruiting from private organisations, 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, three were interested and requested more information.

Service managers from the three interested organisations were sent the interview participant information sheet (Appendix J) and the interview consent form (Appendix K) so that support workers interested in participating had time to read and sign before participating.

Participants - Demographics

Eight support workers, from the three interested organisations (two from two organisations and four from the other), completed semi-structured interviews. Table 1 shows the demographic data for all participants. Inclusion criteria for participation were at least one years' experience working as a support worker, full time, with adults with a learning disability, in a paid role.

Table 1. Participant demographics

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

Interviews

The researcher checked with participants that they had read the participant information sheet and were happy to give their consent to continue.

Participants were also asked to fill in a demographic sheet (Appendix L) to enable the researcher to look for any patterns or themes across age, gender or experience levels. Interviews were recorded with a Dictaphone and took place in supported living service settings, using quiet areas and as least intrusive as possible. Interviews followed the semi-structured question sheet above which was devised to enable participants to explore and expand upon their understanding about their role in supporting people to explore personal and sexual relationships on the internet. Debrief sheets (Appendix M) were explained and given to participants upon finishing the interview.

Data Analysis

Analysis of the data followed the six-staged approach outlined by Braun and Clarke (2013), this process can be seen in Appendix Q. First, audio data from interviews were transcribed. Transcripts were then read through several times, taking note of items of interest. Coding was completed using the

complete coding method, which involves systematically working through the data, looking for large or small chunks of data that potentially relate to the research question and providing a summary label for it, and then sorted into themes and subthemes. Themes were then refined, reviewed, defined and checked back against the research question. Quotes from participants were identified to support the themes generated, and efforts were made to ensure quotes across all participants were used to represent the range views. Feedback from viva voce after first submission, was also considered.

Credibility

Sections of transcript, codes and the thematic map were discussed in a peer supervision group for qualitative research at the University three times. The qualitative research group had between six and nine peers, and between one and three academic tutors present. Discussion about the codes was helpful in generating themes, and in a later session, changes were made to the labels for themes and what the label was trying to summarise.

Reflexivity

The researcher has strong views on the rights of people with learning disabilities, but also the expectations of support workers who are working with adults with learning disabilities. Specifically, the researcher believes that support workers, who are paid to provide a service of support to an adult with a learning disability, should be supporting that person to achieve the life goals that the person may have. Although this is likely to have an impact on the way the data is seen, and the themes that are generated from that, measures were taken to minimise these potential biases, such as the qualitative research group at the University. Additionally, the concept of bracketing (Tufford & Newman, 2010) was helpful in thinking about how to reduce the impact of research bias in qualitative research.

Ethics

Ethical approval for this study was granted by Staffordshire University's Research Ethics Committee (Appendix O). Full, written consent was obtained from each participant before participating, and a full debrief was offered

following participation. All data was anonymised to ensure confidentiality of all participants.

Results

The data collected highlighted the broad range of thoughts and feelings support workers delved into when thinking about how they understand their role of supporting adults with learning disabilities to use the internet for the purposes of personal and sexual relationships. Three main themes were identified;

1) ***Social and Organisational Dilemmas***, containing three subthemes;

- i. *Role and Moral Positioning*
- ii. *Expectations of Support*
- iii. *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 organised beneath a central, candidate theme, of *how support workers understand their role*. Braun and Clarke (2013) suggest that a thematic map, to visually demonstrate how themes are interlinked, can be helpful in giving the reader a useful overview of the findings from a data set, see Figure 1 below.

How support workers understand their role?

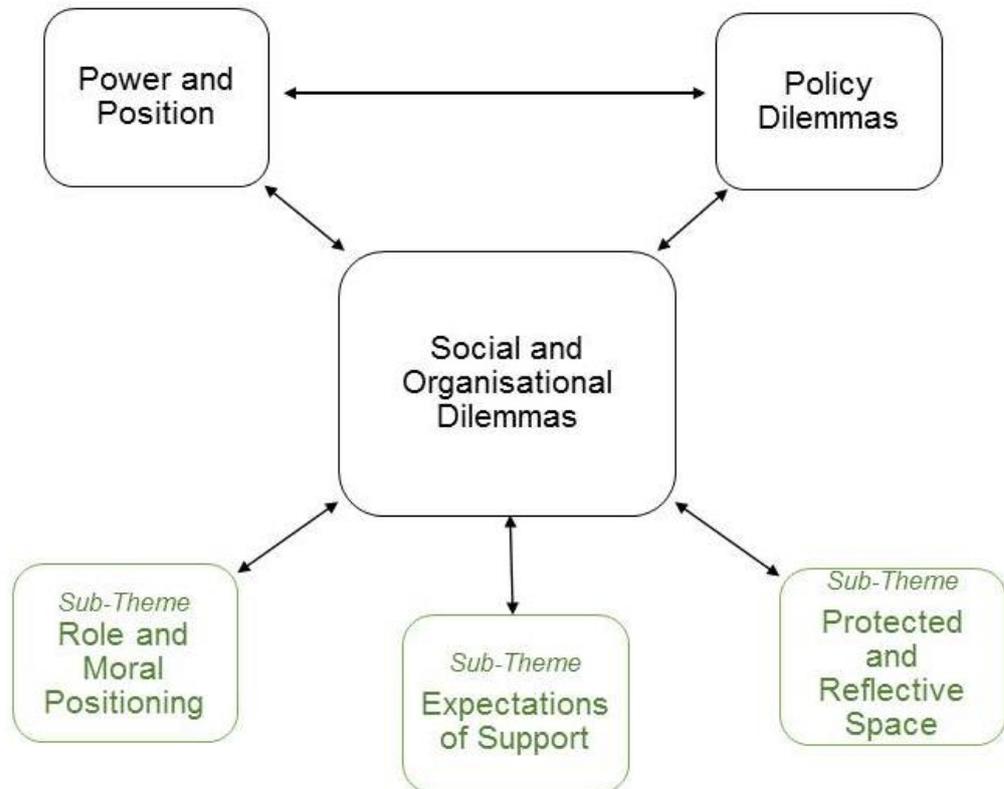


Figure 1. Thematic map demonstrating the relationship between the overarching theme, main themes and subthemes.

Social and Organisational 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 organisational 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 would like to support them as I would myself, be supported if I needed, you know, like, to be treated with dignity and respect.” – Participant 3.

“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.

“...if they can find happiness and find a partner, then I’m all for that, yeah.” – Participant 7.

“...they’re still people, you know, and there’s, most of these are no different to if me or you wanted to go online and do it, you know, its still your right as a person, to go and do, cause it’s a common thing these days isn’t it, to meet somebody online.” – Participant 8.

All participants made similar comments regarding how they make sense of these social and organisational dilemmas, as to how and why people should be supported, particularly around having access to relationships. There was very much 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 learning disabilities.

Role and Moral Positioning

This sub-theme highlights how all participants varied in both their approach to the role of supporting adults with learning disabilities to use the internet for personal and sexual 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 Organisational 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.

“He’s not comfortable sitting on the internet with everybody there, cause obviously some people you know, will literally sit and glare over his shoulder,

where, you know, I'll just tidy around as I'm going, keep flicking over.” – Participant 6.

“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, not necessarily in a negative way, however, 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 its one of the extra things, like above and beyond, you know, its 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.

“Different people have got different views, from different carers...everybody else has different aspects and views of care.” – Participant 3.

“...You're always going to get one or two people in a staff team that don't have a full understanding of why it would be beneficial to somebody. And I think you'd have to do as much work with maybe with some of the staff.” – Participant 4.

“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.

Expectations of Support

The sub-theme of expectations of support is also linked to social and organisational 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 from a social perspective, for others it appears to be a somewhat unclear organisational or professional expectation of the role.

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

“It’s not about doing things for them, its about doing things with them.” – Participant 8.

There were also comments around the idea of being ‘expected to’, it was unclear where this feeling came from, however, the context suggested that

this feeling came from an organisational or professional pressure to do certain things within the role.

“You’ve got no choice but, you know, they’ll be up ‘til three or four o’clock in the morning on the phone, but there’s nothing you can do, you cant go knock on and say I’m taking your phone, I wouldn’t want to anyway because its their personal belongings, so you just deal with what it is.” – Participant 1.

“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.

“It’s hard in our place, because there is only one of you on at a time, to support four people, so it’s a bit limited, I suppose if your doing something for their needs, which meets best interests, then I would make time...come in on my day off.” – Participant 3.

“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.

Protected and Reflective Space

This final sub-theme linked to social and organisational 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, a feeling that there is a deficit in services currently. 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.

“I wish there was a service for it...you could have someone come around and explain to people with learning disabilities, based on their past and based on their ability, to like try and explain the nature of sexuality and dating, and the pitfalls.” – Participant 2.

“...whether it was social workers, or community things, you know, like I could sit with them and have a look online...But I just don’t feel I’ve got enough experience or training, whatever, like that, that I’d be able to inform someone on a decision which could in theory change the rest of their lives.” – Participant 6.

“...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.

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 organisation. There appeared to be a desire for this training, however, the guidance that was available was thought to be around internet use for support workers, rather than supporting adults with learning disabilities to use it. What was clear is that there was no training available for support workers on how to effectively support adults with learning disabilities to use the internet, let alone on how to support them to use the internet for personal and sexual relationships.

“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 its 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.

“At the moment there is no clear – right, this person wants to do this, so we need to do this, we need to get this person involved...there’s no clear line as to how to do it.” – Participant 4.

“I could have a picturesque view of what I think the internet is about but there could be something else out there that I am not aware of. And to be aware of those whilst in work.” – Participant 5.

“...and really, we should be having training cause, its everyday life aint 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 might be guidelines, but I’ve not had any training on it yet no.” – Participant 7.

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 inextricably linked to the social and organisational dilemmas of the individual support worker, and as outlined later, is also linked to how that support worker views themselves in regards to their power and position.

The support worker participants spoke about their role supporting adults with learning 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 make a decision on these dilemmas in the moment – they saw their role is to be able to do that as successfully as possible.

“...we then take on a bigger role, because were trying to do both sides, were trying to support a person that’s being, probably abused by somebody on Facebook in our service, on top of trying to guide our service user to take the correct approach when using different social media sites.” – Participant 1.

“You’ve got to make sure they understand and know what they, they’re getting into, erm, but if they still want to do it, then support them.” – Participant 3.

“They’ve got to live their life independently, as much as they can, but you’ve also got to make sure that they’re not going to be in any danger.” –

Participant 4.

“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.

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 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 personal or sexual relationships online.

“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.

Power and Position

The final main theme generated from this data set highlights the different power and positions the support workers take within their role, particularly around risk management when it came to how they might support adults with learning disabilities to use the internet for personal and sexual 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.

“You’ve got to respect their confidentiality, but you’ve also got to make sure that they’re safe.” – Participant 2.

“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 its 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.

There was also some concern about the risk of something unpleasant or terrible happening to the people they are supporting, and how it makes them feel. This position of feeling guilty or blaming themselves could be a limiting factor in how far support workers were willing to go in supporting an adult with learning disabilities to use the internet, particularly for sexual relationships.

“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.

Finally, a couple of support workers spoke about the dangers of internet supporting spilling over into physical difficulties. One support worker spoke about an example of a person they had supported and the difficulties which came from that. These considerations could add another layer of potential risk in the consideration process when support workers are thinking about how the support a person online with personal and sexual relationships.

“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.

Discussion

The findings of this thematic analysis offer insight into how support workers understand their role in supporting adults with learning disabilities to access the internet for the purposes of personal and sexual relationships. Participant support workers all felt that building personal and sexual relationships was an important and worthwhile pursuit for adults with learning disabilities.

However, there appeared to be dilemmas for individual support workers to make decisions on how much they believed this to be part of their role as a support worker, particularly regarding using the internet for these purposes. Some participant support workers felt that it was very much part of their role, and took an open, advising, ‘let’s see what happens’ approach; others felt

clear that it was not part of their role. Findings also suggest that individual support workers form part of a diverse, wider team of support workers, holding a variety of views and positions on what the support role should look like. As frontline staff, one might think that support workers would have a role in service implementation and development; however, organisations often limit the capacity for support workers to contribute to this (Qualliam, Bigby & Douglas, 2017).

The research outlined in this paper considered how the attitudes of support workers impacted on how they support adults with learning disabilities to explore sexual and personal relationships (Hamilton, 2008; Saxe & Flanagan, 2013), but also with respect to sexuality (Andrea, 2011) and attitudes towards sexuality (Grieve et al., 2009). Differences in attitude could be considered in terms of the findings from this paper; the central theme of social and organisational dilemmas and its sub-themes, show a continuum in how support workers view their role of supporting adults with learning disabilities use the internet for personal and sexual relationships. The research conducted by Mason et al. (2012) which found that support workers are often seen as 'key holders' is pertinent to the findings here. With such variance in support workers and with a lack of training opportunities, the support that an adult with a learning disability receives to use the internet for personal and sexual relationships is highly dependent upon the support workers own sense of how to manage the dilemmas of the role – built upon their experiences and expectations, without necessarily having organisational guidance or training.

Previous research has highlighted the challenges and dilemmas that support workers face when supporting adults with learning disabilities to use the internet, in terms of weighing-up risk, privacy and appropriacy (Chadwick, Wesson & Fullwood, 2013). This was also described by participants here, they saw part of their role regarding this research topic as having the ability to weigh up the situation and make in-moment decisions on how best to support a person, specifically keeping the balance between risk and safety in mind. This process of managing dilemmas on the appropriate actions was central to the role of the support workers, however, there was also an

acknowledgement that there is no training or guidance from their respective organisations in how to do this. Organisations offering little to no training or guidance for the participant support workers is also highlighted in previous research (Windley & Chapman, 2010), perhaps disappointingly, this is still the case nearly ten years on from this research.

Considering the thoughts on additional training from a different angle, the idea of a moral compass (Bennett, 1995) may be relevant here as a metaphor for the inner voice which tells us what we should or should not do. Findings suggest that support workers approach the dilemmas which arise in their role from a moral position which impacts on what their support looks like. Further training or guidance may not be effective in shifting this moral position, and then there are ethical debates about who is to decide if that moral position should be shifted at all. Although some researchers believe training can have an impact on a person's moral compass (Moore & Gino, 2013).

Within this broader idea of dilemmas were comments about capacity. Support worker participants 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 or make decisions. It appears that there is a lack of understanding about the Mental Capacity Act (2005) and this has significant implications for how people are supported. The participants used the term to prevent them 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; further training was recommended there. Research appears to be sparse regarding the Mental Capacity Act and the degree in which support workers who work with adults with learning disabilities understand it – a notable gap in the research.

Future Research

It is important to explore the views and experiences of adults with learning disabilities who are attempting to access the internet for personal and sexual relationships with support, both successfully and unsuccessfully. As well as comparing the expectations, hopes and assumptions that adults with learning disabilities have about the role of their support staff in terms of supporting them to access the internet for these purposes. There is value in this, particularly if the expectations are clearly unaligned, as there could be implications for support workers, services and service providers that claim to promote independence and inclusivity. Exploring how organisations understand their own role and responsibilities in providing support for adults with learning disabilities to access the internet for personal and sexual relationships, from training staff, developing policy and guidance, to equipment and resources, is essential.

Strengths and Limitations

This research started with an initial consultation focus group, allowing the researcher to build a semi-structured interview schedule which considered some views and ideas from adults with learning disabilities who are currently using the internet for personal and/or sexual relationships. Another strength of this research is that it is an under researched area, but one that is becoming increasingly important due to the increased numbers of people with learning disabilities using the internet for such purposes.

A limitation of this study refers to the participant demographics, it is a study that is based on views of support workers in the West Midlands area of England and may not be representative of the wider support worker group both nationally and globally. Participants who did not work full time were excluded from this study, this was to ensure the participants had enough experience to make informed comments; it may be worthwhile including part-time staff in future studies. Participants were sourced from three different organisations, whilst this appeared to be fair coverage for the scale of this study, there are potentially organisations who may provide training or guidance, which have not been covered by this research. Interviewing

support workers who have received this training or support may offer different views on how they understand their role.

Inevitably, the views, beliefs, experiences and attitude of the researcher, which were outlined previously, may impact upon 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 regarding what is expected in their role. It is important to recognise that support workers, who are working with adults with learning 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 which allowed the researcher to think critically about the research journey and consider any biases which may have come from that. 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.

Clinical Implications

A lack of guidance and training opportunities for support workers has not only been found in previous research, but also in this study. Without this, how support workers understand their role supporting adults with learning disabilities to use the internet for personal and sexual relationships is shaped by individual beliefs, values and experiences. This means that the support an adult with learning disabilities receives to do this 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 support workers who support adults 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, organisations who provide support and adults with learning disabilities. 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, organisational and policy dilemmas appeared to be central to how they understand their role here. 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.

In times of austerity, uncertainty and service financial strain, it seems more pertinent than ever that support workers should be able to make informed decisions about how they enable a person to use the internet for personal and sexual relationships, before requiring other professionals to come in and provide that guidance and support. There are implications here for the organisations that employ those support workers, to provide support, guidance and time, to access training and have the opportunity to develop that knowledge.

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 learning 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 learning 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 organisational dilemmas about sexuality for people with learning 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 'key holders' by adults with learning 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 organisations that employ support workers who work with adults with learning disabilities.

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Paper 3: Executive Summary

An accessible summary of research outlined in paper 2.

“How do support workers, supporting adults with learning disabilities, understand their role in facilitating access to the internet, for the purposes of personal and sexual relationships?”

Word count: 2,378

This paper is not intended for publication. It has been written in the style of a report aimed at support workers and organisations who employ support workers, that participated in the research or who have an interest in the findings from this research. It also includes a research summary for adults with learning disabilities, which will be offered to the those that participated in the initial focus group and others who are interested in the research.

Research Summary



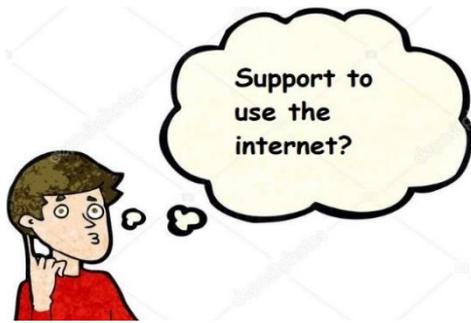
Lots of people are using the internet to make friends or find partners.



Some people with learning disabilities need support to do this.



A focus group of people with learning disabilities spoke about this. They helped the researcher to make questions to ask support workers about supporting to use the internet.



Support workers were asked about how they might support people to use the internet to make friends or find partners.



Some support workers said they should support with that, some said that they should not.



Support workers said that they have never had any training about how to support someone with it.



This research said that companies who employ support workers should offer training on how to support someone to use the internet to make friends or find partners.

Background

Using the internet is part of daily life for most people (Office of National Statistics, 2018), from online shopping and house hunting to job applications and working from home. Using the internet for building and maintaining friendships and developing new sexual relationships has also become mainstream, with many new relationships starting online. Adults with learning disabilities are, like many, also looking to use the internet for personal and sexual relationships, however, there are additional difficulties for them because of limited available support and concerns about risk management.

Support workers have the challenge of providing support to facilitate access to the internet for personal and sexual relationships, but also to manage risk, safety, privacy and make judgements about what is and is not appropriate. Alongside these challenges, there is a tendency to avoid taking risks and organisations appear to offer little to no training in how they might provide support to use the internet for personal and sexual relationships (Windley & Chapman, 2010).

Previous research (Mason *et al.*, 2013) has shown that some adults with learning disabilities see their support workers as 'key holders' to activities – where activities are only possible if the support worker is involved. The idea of key holding is a powerful one as it emphasises the role that support workers have in providing a role and moral positioning, from personal care and finance management, to accessing the community, building new friendships and using the internet. Significantly, how support workers understand their role in providing support to facilitate access to the internet for personal and sexual relationships will impact on what that support will look like – and if there is little organisational support or training for this, it is down to individual support workers personal views as to how they make sense of that.

- This report outlines findings from a study which looked at how support workers, supporting adults with learning disabilities, understand their role in facilitating access to the internet, for the purposes of personal and sexual relationships.

Method

Ethical approval was granted for this study by Staffordshire University's Ethical Committee. All data was anonymised and held securely in locked storage and encrypted data sticks, all participants were offered an information sheet and consent form before participating and were given a debrief sheet after taking part in the study.

A focus group of adults with learning disabilities was consulted to discuss the research topic. This discussion allowed the researcher to create interview questions which were shaped by individuals who are currently accessing support to use the internet, thereby giving the interview questions additional relevance.

Following the focus group; eight support worker participants, who are currently supporting adults with learning disabilities, from the West Midlands area of England, United Kingdom, were interviewed. The participants were asked about how they understand their role in supporting adults with learning disabilities to access the internet for personal and sexual relationships. Interviews were conducted one-to-one and took place in support living service settings. Interviews were audio recorded, then transcribed on computer.

Interview data was analysed using thematic analysis (Braun and Clarke, 2013). A six-step process was used; data was transcribed, then read several times by the researcher to get familiar with it and note items of interest. The data was then coded, which involves trying to provide concise labels for chunks of transcript that relate to the research topic. Then themes were tentatively generated and discussed with a study group at the university. Finally, the themes were defined and mapped.

Findings

Themes found across the data set showed that support workers had a broad range of thoughts and feelings when thinking about how they understand their role of supporting adults with learning disabilities to use the internet for the purposes of personal and sexual relationships. Three main themes were identified and were considered as highly interconnected, one of those themes

has three sub-themes. The thematic map shows the themes and how they are connected to each other, shown below in Figure 1. Quotes from participating support workers are also outlined, which illustrate and support how the researcher generated these themes.

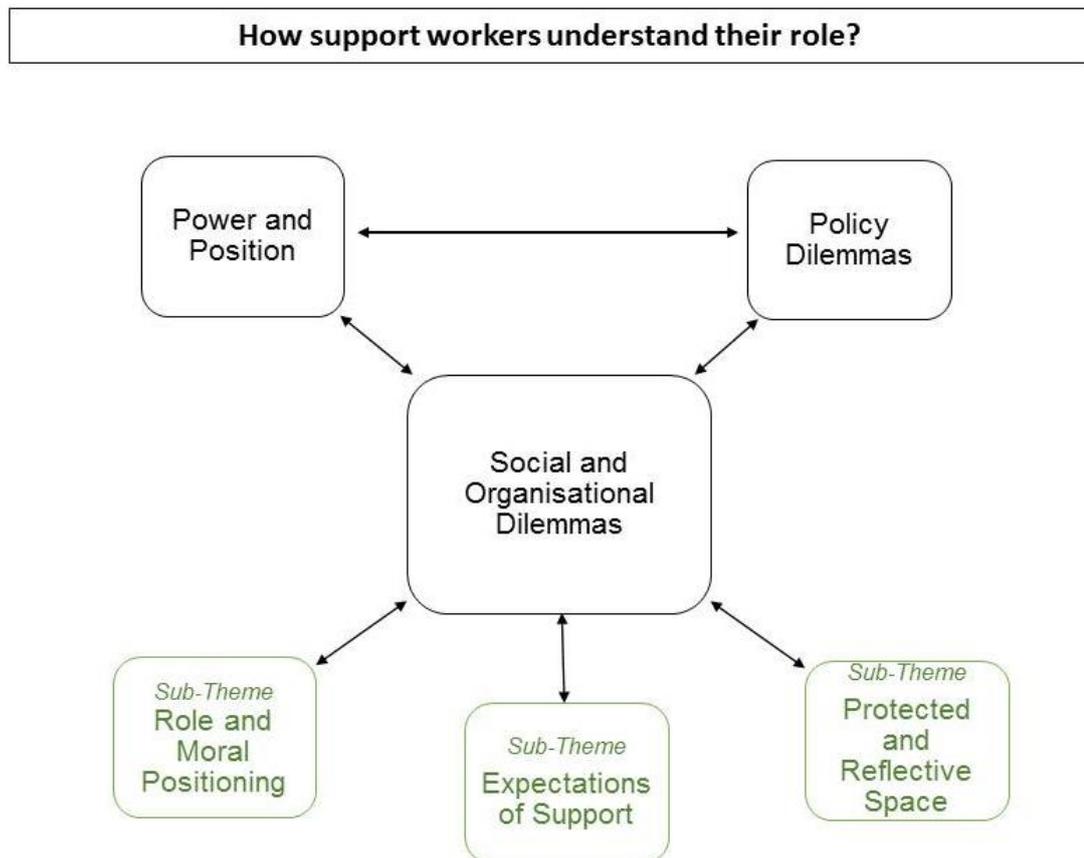


Figure 1. Thematic map demonstrating the relationship between the overarching theme, main themes and subthemes.

Social and Organisational dilemmas

As the thematic map suggests, this main theme appears to be central in how support workers understood their role – how and why they support came from a sense or belief in the dilemmas of what should be done. Three sub-themes also feed into this theme; role and moral positioning, expectations of support and protected and reflective space – these will be outlined next. All support workers felt that all adults with learning disabilities should be able to pursue and engage in relationships.

“Everyone wants to be loved, don’t they?”

– Participant 2.

“I would like to support them as I would myself, be supported if I needed, you know, like, to be treated with dignity and respect.”

– Participant 3.

Role and moral positioning

This sub-theme of social and organisational dilemmas showed how support workers had a varied approach about how they might support someone to use the internet for personal and sexual relationships, but also how they felt other support workers do this. Some support workers said they would intervene directly, whereas others were more willing to step-back and ‘see what happens’.

“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.

“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.

Expectations of Support

The second sub-theme of social and organisational dilemmas showed what support workers considered the expectations of their role and where those expectations come from. There was a broad range of expectations of how they should support adults with learning disabilities to use the internet for personal and sexual relationships; from a broad and open ‘see how it goes’ approach, to something more rigid or not seen within their role at all. There also appeared to be organisational pressures which impacted upon their expectations.

“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 hard in our place, because there is only one of you on at a time, to support four people, so it’s a bit limited, I suppose if you’re doing something for their needs, which meets best interests, then I would make time...come in on my day off.”

– Participant 3.

Protected and reflective space

The final sub-theme of social and organisational dilemmas highlighted how support workers valued spaces where input from senior team members, managers, and external professionals could input; however this was often in the context of a lack of training or lack of guidance.

“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.

“At the moment there is no clear – right, this person wants to do this, so we need to do this, we need to get this person involved...there’s no clear line as to how to do it.”

– Participant 4.

Power and position

The second main theme suggests that support workers see their role as one of continuously reflecting on their position and weighing-up and making in moment decisions based on the situation. Support workers were considering thoughts about whether the person they are supporting fully understands what they wish to engage in, risk and how best to monitor them; they also

used the term 'capacity', suggesting that they also saw it as part of their role to assess or make judgements about a person's ability to make decisions.

"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.

"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.

Policy dilemmas

The final main theme showed how support workers saw their role in supporting adults with learning disabilities to use the internet for personal and sexual relationships in terms of policy dilemmas. For all support worker participants in this study, there was a clear process that involved thinking about the positive benefits of taking a risk and supporting someone to meet someone from the internet versus the safety concerns that come with that.

"You've got to respect their confidentiality, but you've also got to make sure that they're safe."

– Participant 2.

"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.

Conclusion

The findings from this study offer insight into how support workers understand their role in facilitating access to the internet for personal and sexual relationships for the people they support. All participant support workers felt that adults with learning disabilities should have support for this; however, they all varied in whether they felt it was part of their role to do so.

If support workers are often seen as 'key holders', then variance in how support workers understand their role and a lack of training opportunities will impact heavily on the support an adult with a learning disability receives to

use the internet for personal and sexual relationships. This support appears to be highly dependent on the support workers own understanding of social and organisational dilemmas – built from their own experiences and expectations, without organisational guidance or training.

The lack of training or guidance for support workers in how to support adults with learning disabilities to use the internet for personal and sexual relationships has been highlighted for many years and is also found in this research also. This gap in training and guidance has been present for too long and must now be addressed by those organisations employing support workers.

Limitations

- Support workers were chosen from the West Midlands area of England only, this limits the generalisability of these findings.
- Support workers from only three organisations were sourced, other organisations may offer training that has been missed here.
- Only those support workers in full-time employment were chosen, meaning experienced part-time workers were excluded.

Recommendations & Future Research

- Training packages and guidance to be created for support workers in how to approach supporting adults with learning disabilities to use the internet for personal and sexual relationships.
- Training packages should be constructed by adults with learning disabilities, support workers and external professionals.
- Organisations that employ support workers should ensure their support workers are given the time and help to access training, with continued support and guidance.
- Future research could look to involve support workers who are experienced but work part-time.
- Future research could also look to extend to other areas of England and in other countries.

Dissemination

- The full research article will be submitted to the British Journal of Applied Research in Intellectual Disabilities.
- The research summary will be presented and discussed with the adults with learning disabilities who took part in the focus group.
- This executive summary will be made available the support workers, and their employing organisations, who took part in the study.

References & Supporting Information

Data on Internet Use in the United Kingdom

The Office for National Statistics suggests that 89% of all adults in the United Kingdom use the internet weekly, up from 51% in 2006.

Office for National Statistics (2018). *Internet access – households and individuals, Great Britain - Office for National Statistics: 2018*.

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<https://www.ons.gov.uk/peoplepopulationandcommunity/householdcharacteristics/homeinternetandsocialmediausage/bulletins/internetaccesshouseholdsandindividuals/2018>. Accessed: (03/02/2019).

Research on support workers training needs

This research examined support workers working with adults with learning disabilities perceived the training offered by organisations; they felt that they need more training and that organisations were quite risk averse.

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>

Research on support workers as 'key holders'

This research was conducted in 2013 which looked at how people with learning disabilities make sense of friendship; it found that support workers were often seen as key holders to activities. For more information, please read the paper.

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>

Thematic Analysis

This involves looking at data, such as a set of transcribed interviews, reading through it carefully and finding codes which summarise chunks of texts in a couple of words. Using the codes, the researcher looks for wider themes across all the data, such as those found within this study. For more information about thematic analysis look at Braun and Clarke's book.

Braun, V. & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. London: Sage.

Appendix

Appendix A. Critical Appraisal Tool for Quantitative Papers

- 1) Is the hypothesis/aim/objective of the study clearly described?
- 2) Did the study explain the scientific background and rationale?
- 3) Have ethical issues been taken into consideration?
- 4) Was the sample for the study sufficiently large and representative?
- 5) Are characteristics of the participants included in the study clearly described?
- 6) Was a questionnaire the most appropriate method?
- 7) Was the method of distribution and administration reported?
- 8) Were response rates reported?
- 9) Have potential response biases been reported?
- 10) Were the statistical tests, if used, appropriate to assess the main outcomes?
- 11) Were all relevant data reported?
- 12) Are significant results reported, and are relevant non-significant results also reported?
- 13) Are the main findings of the study clearly described?
- 14) Have the researchers drawn an appropriate link between the data and their conclusions?
- 15) Have limitations of the study been discussed?
- 16) Was generalisability discussed/considered?

Scoring

Key: Y=Yes, N=No, P= Partially, UK= Unable to determine, N/A= not applicable

Scoring: Y=2 points, P=1 point, N=0 points, UK=0 points

Appendix B. Critical Appraisal Scoring Table

Paper	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	Total	%
Lough & Fisher	Y	Y	P	P	Y	Y	Y	Y	N	Y	Y	Y	Y	P	Y	Y	27/32	84.38
Chiner, Gomez-Puerta & Cardona- Molto	Y	Y	P	Y	Y	Y	Y	Y	P	Y	Y	P	Y	Y	Y	Y	29/32	90.63
Chadwick, Quinn & Fullwood	Y	Y	P	P	Y	Y	Y	Y	Y	Y	Y	Y	Y	P	Y	Y	29/32	90.63
Lofgren- Martenson, Sorbing & Molin	Y	Y	Y	P	Y	P	Y	P	Y	Y							17/20	85
Hegarty & Aspinall	Y	Y	Y	P	P	P	P	Y	Y	Y							16/20	80
Li-Tsang, Yeung, Chan & Hui-Chan	Y	Y	N	Y	Y	Y	Y	Y	P	Y	P	Y	Y	Y	N	P	25/32	78.13
Chiner,	Y	Y	N	Y	Y	Y	Y	Y	P	Y	Y	Y	P	Y	P	P	26/32	81.25

Gomez-Puerta & Cardona-Molto																			
(Quantitative Element) Sallafranque-St-Louis & Normand	Y	Y	Y	P	P	Y	P	Y	P	Y	Y	Y	Y	P	Y	Y	27/32	84.38	
Carey, Friendman & Bryen	Y	P	N	Y	Y	Y	Y	Y	P	Y	Y	Y	Y	P	Y	Y	27/32	84.38	
(Qualitative Element) Sallafranque-St-Louis & Normand	Y	Y	P	P	Y	Y	Y	P	Y	Y							17/20	85	

Scoring

Key: Y=Yes, N=No, P= Partially, UK= Unable to determine, N/A= not applicable

Scoring: Y=2 points, P=1 point, N=0 points, UK=0 points

Appendix C. Data Extraction Table

Record	Author(s), Date, Country	Title	Sample	Methods	Key Findings	Strengths	Limitations	Criteria met by critical appraisal tool (%)
1	Lough and Fisher 2016 USA	Internet use and online safety in adults with Williams Syndrome	28 Adults with Williams Syndrome (22 male) (Mean age 27.7 years) And parents (25 mothers) (mean age 56.9)	Online questionnaire and E-safety scenarios. T-tests.	High levels of internet use among group, particularly social media. Parental supervision levels were low. Individuals with Williams syndrome were willing to share lots of identifiable data on social media and were more likely to engage in risky behaviours related to socialising compared to non- social activities.	Clear method, innovative methods. Focus on findings, linked from intro to results. Future consideration mentioned, a focus on risk and safety for individuals with WS and ID more broadly.	Noted: Small sample size, all sample from one specific group, group members likely to be more independent and able than peers. No control group.	84.38
2	Chiner, Gomez- Puerta and Cardona-	Internet use, risks and online behaviour: The view of	77 Adults with Intellectual Disability (49 male)	Questionnaire, 3 versions.	Carers more likely to use computers than family members.	Validity checks. Large sample size.	Many non- responders. Noted: Single organisation.	90.63

	Molto 2017b Spain	internet users with intellectual disabilities and their caregivers	(Mean age 25.31 years) 68 caregivers (40 family) (26 male) (mean age 51.03 years)		Smartphone use was very high. Many individuals had equipment taken away if there were problems or difficulties. Easier to go online in recent years, high rates of people online. Care givers need more awareness re: the potential benefits of internet for people with intellectual disabilities.	Findings clear and relate to the rationale.	Low response rate of families. Socially desired responses? Impairments impacting on survey answers?	
3	Chadwick, Quinn and Fullwood 2016 UK	Perceptions of the risks and benefits of internet access by people with intellectual disabilities	166 adults (131 female) (mean age =25.35)	Survey questionnaire, 129 completed online, 37 by post. Repeated measures MANOVA.	Benefits perceived as high for adults with intellectual disabilities and would promote inclusion. Misconceptions about accessibility and risks. Future research should focus on the gatekeepers to	Large sample, diverse. Results link to rationale. Future research considered.	Sample location, generalisability? Lay population, many no contact with people with intellectual disabilities.	90.63

					internet access (eg carers) and their own perceptions of risk.			
4	Lofgren-martenson, Sorbing and Molin 2015 Sweden	Tangled up in blue: Views of parents and professionals on internet use for sexual purposes among young people with intellectual disabilities	13 adults (8 professionals, 7 female. Ages 38-58) (5 parents, 3 female, ages 47-57)	Focus groups, or paired interviews. Semi-structured interviews. Thematic analysis.	3 main themes around 'the arena'. 1) love and sexuality, hope and sorrow. 2) sexual conduct. 3) sexual risks. Conflicting views on risks and benefits. Highlights importance of views and perspectives of parents and professionals for future research.	Reflexivity well considered. Themes clear, with overlap. Rationale clear and links intro to results.	Noted: limited data, female heavy sample. Professional sample included only active teachers from one school.	85
5	Hegarty and Aspinall 2006 UK	The use of personal computers with adults who have developmental disabilities: Outcomes of an organisation wide initiative	Upto 750 adults with intellectual disabilities using this organisations day services.	Service evaluation/Qualitative programme evaluation. Observations, interviews and photographs.	Includes a focus on internet use. Services were shown to be supportive of computer and internet use across the services. Highlighted importance of staff	Detailed report. Outlines aims and results, matches rationale. Observational over a long period of time inclusive	Noted: focus on one organisation only, specific ICT equipment used. Different organisations may have different priorities on ICT	80

					training, both in how to support and using the systems themselves. Future research should examine inclusion through ICT and internet usage for individuals with intellectual disabilities.	of a high number of services across the country.	and internet usage.	
6	Li-Tsang, Yeung, Chan and Hui-Chan 2005 Hong Kong	Factors affecting people with intellectual disabilities in learning to use computer technology	350 adults with intellectual disabilities (adults here defined as 16+) (219 male, mean age = 28.77) Individuals attending day centres or day workshops.	Competency checklist developed as a measure. Witnessed levels ticked off the checklist as individual completes instruction. Spearman's and T-tests used. Parent and caregiver survey also used.	Limited training opportunities for both people with intellectual disabilities and caregivers. Differences in competencies based on levels of intellectual disability. Most people's homes and day services had computers in, but competence levels	Large sample size. Methods went through some validation processes. Range of people with intellectual disabilities and support staff/carers considered and included.	Unclear methods make replication difficult. Cultural and financial circumstances not considered.	78.13

					were still low. Caregivers/staff hesitant to provide support due to worry of risk. Future research to consider position and perceptions of caregivers/staff.			
7	Chiner, Gomez-Puerta and Cardona-Molto 2017a Spain	Internet and people with intellectual disabilities: an approach to caregivers concerns, prevention strategies and training needs	44 caregivers (20 family, 24 care staff) (18 males) (mean age 48) (Average experience of staff 13.11 years)	Questionnaire (2 versions) 56% return rate (staff) 14% (family). 16 removed as unfinished. Descriptive analysis, Mann-Whitney U to look at differences between staff and parents.	Overall low levels of training reported. Half of the sample said they were prepared to cope with problems encountered on the internet for the people they are supporting. Internet was deemed less safe for people with intellectual disabilities, especially around revealing personal information. Both groups	Method clear and replicable. Intro and results linked to rationale, clear reasons.	Noted: only used one organisation, low response rates and reasons why unclear.	81.25

					wanted to promote positive risk taking, but felt they needed more training for this. Future research should focus on those providing the support to individual with intellectual disabilities			
8	Sallafranque-St-Louis and Normand 2017 Canada	From Solitude to Solicitation: How people with intellectual disabilities or ASD use the internet	8 adults (5 with intellectual disabilities of which 3 were male) (3 with ASD of which 2 were male) (mean age 25)	Mixed method: Questionnaire and descriptive statistics Interviews and content analysis (1 participant completed the questionnaire but declined the interview)	Accessing the internet at home came with rules, controls and cost factors. Varied smartphone access levels, but smartphones becoming increasingly used. No credit card access makes online shopping difficult. Confiscation of equipment had occurred for some individuals due to	Triangulation well documented, validity and reliability discussed. Rationale clear. Results linked to intro.	Noted: small sample size, unclear causes, 3 ASD not main focus of paper.	Quantitative: 84.38 Qualitative: 85

					masturbation. Generational differences in people with intellectual disabilities, those over 30 and those under 30?			
9	Carey, Friedman and Bryen 2005 USA	Use of electronic technologies by people with intellectual disabilities	83 adults with an intellectual disability (35 males) (mean age = ??)	Survey questionnaire Descriptive statistics Chi-square	Computer use around 41%, internet use at 25%. Age, employment and perceived ability to cope affected use of the internet. Support from staff may be more important than thought. Attitudes of support staff requires further research.	Large diverse sample. Clear rationale, linked to intro and results.	Noted: income not well considered as unknown mostly. Consistency of questions on survey and impact for those with intellectual impairments unknown.	84.38

Appendix D. Submission guidelines for the Journal of Applied Research in Intellectual Disabilities

Retrieved from:

<https://onlinelibrary.wiley.com/page/journal/14683148/homepage/ForAuthors.html> (03/08/2018)

Author Guidelines

Crosscheck

The journal to which you are submitting your manuscript employs a plagiarism detection system. By submitting your manuscript to this journal you accept that your manuscript may be screened for plagiarism against previously published works.

1. GENERAL

The *Journal of Applied Research in Intellectual Disabilities* is an international, peer-reviewed journal which draws together findings derived from original applied research in intellectual disabilities. The journal is an important forum for the dissemination of ideas to promote valued lifestyles for people with intellectual disabilities. It reports on research from the UK and overseas by authors from all relevant professional disciplines. It is aimed at an international, multi-disciplinary readership.

The topics it covers include community living, quality of life, challenging behaviour, communication, sexuality, medication, ageing, supported employment, family issues, mental health, physical health, autism, economic issues, social networks, staff stress, staff training, epidemiology and service provision. Theoretical papers are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. All original and review articles continue to undergo a rigorous, peer-refereeing process.

Please read the instructions below carefully for details on submission of manuscripts, the journal's requirements and standards as well as information concerning the procedure after a manuscript has been accepted for publication. Authors are encouraged to visit <http://authorservices.wiley.com/bauthor/> for further information on the preparation and submission of articles.

All manuscripts must be submitted solely to this journal and not published, in press, or submitted elsewhere.

2. ETHICAL GUIDELINES

Acceptance of papers is based on the understanding that authors have treated research participants with respect and dignity throughout. Please see Section 2.2 below.

2.1 Authorship and Acknowledgements

Authorship: Authors submitting a paper do so on the understanding that the manuscript has been read and approved by all authors and that all authors agree to the submission of the manuscript to the journal. ALL named authors must have made an active contribution to the conception and design and/or analysis and interpretation of the data and/or the drafting of the paper and ALL authors must have critically reviewed its content and have approved the final version submitted for publication. Participation solely in the acquisition of funding or the collection of data does not justify authorship.

It is a requirement that all authors have been accredited as appropriate under submission of the manuscript. Contributors who do not qualify as authors should be mentioned under Acknowledgements.

Acknowledgements: Under Acknowledgements please specify contributors to the article other than the authors accredited. Please also include specifications of the source of funding for the study and any potential conflict of interest if appropriate. Suppliers of materials should be named and their location (town, state/county, country) included.

2.2 Ethical Approvals

Research involving human participants will only be published if such research has been conducted in full accordance with ethical principles, including the World Medical Association Declaration of Helsinki (version, 2002 www.wma.net) and the additional requirements, if any, of the country where the research has been carried out. Manuscripts must be accompanied by a statement that the research was undertaken with the understanding and written consent of each participant (or the participant's representative, if they lack capacity), and according to the above mentioned principles. A statement regarding the fact that the study has been independently reviewed and approved by an ethical board should also be included.

All studies using human participants should include an explicit statement in the Material and Methods section identifying the review and ethics committee approval for each study, if applicable. Editors reserve the right to reject papers if there is doubt as to whether appropriate procedures have been used.

Ethics of investigation: Papers not in agreement with the guidelines of the Helsinki Declaration as revised in 1975 will not be accepted for publication.

2.3 Clinical Trials

Clinical trials should be reported using the CONSORT guidelines available at www.consort-statement.org. A CONSORT checklist should also be included in the submission material (www.consort-statement.org).

The *Journal of Applied Research in Intellectual Disabilities* encourages authors submitting manuscripts reporting from a clinical trial to register the trials in any of the following free, public trials registries: www.clinicaltrials.org, www.isrctn.org. The clinical trial registration number and name of the trial register will then be published with the paper.

2.4 Conflict of Interest and Source of Funding

Conflict of Interest: Authors are required to disclose any possible conflict of interest. These include financial (for example patent ownership, stock ownership, consultancies, speaker's fee). Author's conflict of interest (or information specifying the absence of conflict of interest) will be published under a separate heading.

The *Journal of Applied Research in Intellectual Disabilities* requires that sources of institutional, private and corporate financial support for the work within the manuscript must be fully acknowledged, and any potential conflict of interest noted. As of 1st March 2007, this information is a requirement for all manuscripts submitted to the journal and will be published in a highlighted box on the title page of the article. Please include this information under the separate headings of 'Source of Funding' and 'Conflict of Interest' at the end of the manuscript.

If the author does not include a conflict of interest statement in the manuscript, then the following statement will be included by default: 'No conflict of interest has been declared'.

Source of Funding: Authors are required to specify the source of funding for their research when submitting a paper. Suppliers of materials should be named and their location (town, state/county, country) included. The information will be disclosed in the published article.

2.5 Permissions

If all or parts of previously published illustrations are used, permission must be obtained from the copyright holder concerned. It is the author's responsibility to obtain these in writing and provide copies to the Publishers.

2.6 Copyright Assignment

If your paper is accepted, the author identified as the formal corresponding author for the paper will receive an email prompting them to login into Author Services; where via the Wiley Author Licensing Service (WALS) they will be able to complete the license agreement on behalf of all authors on the paper.

For authors signing the copyright transfer agreement

If the OnlineOpen option is not selected the corresponding author will be presented with the copyright transfer agreement (CTA) to sign. The terms and conditions of the CTA can be previewed in the samples associated with the Copyright FAQs below:

CTA Terms and Conditions http://authorservices.wiley.com/bauthor/faqs_copyright.asp

3. ONLINEOPEN

For authors choosing OnlineOpen

If the OnlineOpen option is selected the corresponding author will have a choice of the following Creative Commons License Open Access Agreements (OAA):

Creative Commons Attribution License OAA

Creative Commons Attribution Non-Commercial License OAA

Creative Commons Attribution Non-Commercial -NoDerivs License OAA

To preview the terms and conditions of these open access agreements please visit the Copyright FAQs hosted on Wiley Author

Services http://authorservices.wiley.com/bauthor/faqs_copyright.asp and

visit <http://www.wileyopenaccess.com/details/content/12f25db4c87/Copyright--License.html>.

If you select the OnlineOpen option and your research is funded by The Wellcome Trust and members of the Research Councils UK (RCUK) you will be given the opportunity to publish your article under a CC-BY license supporting you in complying with Wellcome Trust and Research Councils UK requirements. For more information on this policy and the Journal's compliant self-archiving policy please visit: <http://www.wiley.com/go/funderstatement>.

4. SUBMISSION OF MANUSCRIPTS

Submissions are now made online using ScholarOne Manuscripts (formerly Manuscript Central). To submit to the journal go to <http://mc.manuscriptcentral.com/jarid>. If this is the first time you have used the system you will be asked to register by clicking on 'create an account'. Full instructions on making your submission are provided. You should receive an acknowledgement within a few minutes. Thereafter, the system will keep you informed of the process of your submission through refereeing, any revisions that are required and a final decision.

4.1 Manuscript Files Accepted

Manuscripts should be uploaded as Word (.doc) or Rich Text Format (.rtf) files (not write-protected) plus separate figure files. GIF, JPEG, PICT or Bitmap files are acceptable for submission, but only high-resolution TIF or EPS files are suitable for printing.

To allow double-blinded review, please upload your manuscript and title page as **separate** files.

Please upload:

1. Your manuscript without title page under the file designation 'main document'.
2. Figure files under the file designation 'figures'.
3. Title page which should include title, authors (including corresponding author contact details), acknowledgements and conflict of interest statement where applicable, should be uploaded under the file designation 'title page'.

All documents uploaded under the file designation 'title page' will not be viewable in the HTML and PDF format you are asked to review at the end of the submission process. The files viewable in the HTML and PDF format are the files available to the reviewer in the review process.

Please note that any manuscripts uploaded as Word 2007 (.docx) will be automatically rejected. Please save any .docx files as .doc before uploading.

4.2 Blinded Review

All articles submitted to the journal are assessed by at least two anonymous reviewers with expertise in that field. The Editors reserve the right to edit any contribution to ensure that it conforms with the requirements of the journal.

By submitting a manuscript to or reviewing for this publication, your name, email address, and affiliation, and other contact details the publication might require, will be used for the regular operations of the publication, including, when necessary, sharing with the publisher

(Wiley) and partners for production and publication. The publication and the publisher recognize the importance of protecting the personal information collected from users in the operation of these services, and have practices in place to ensure that steps are taken to maintain the security, integrity, and privacy of the personal data collected and processed. You can learn more at <https://authorservices.wiley.com/statements/data-protection-policy.html>.

5. MANUSCRIPT TYPES ACCEPTED

Original Articles, Review Articles, Brief Reports, Book Reviews and **Letters to the Editor** are accepted. **Theoretical Papers** are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. Articles are accepted for publication only at the discretion of the Editor. Articles should not exceed 7000 words. Brief Reports should not normally exceed 2000 words. Submissions for the Letters to the Editor section should be no more than 750 words in length.

6. MANUSCRIPT FORMAT AND STRUCTURE

6.1 Format

Language: The language of publication is English. Authors for whom English is a second language must have their manuscript professionally edited by an English speaking person before submission to make sure the English is of high quality. It is preferred that manuscripts are professionally edited. A list of independent suppliers of editing services can be found at http://authorservices.wiley.com/bauthor/english_language.asp. All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

6.2 Structure

All manuscripts submitted to the *Journal of Applied Research in Intellectual Disabilities* should include:

Cover Page: A cover page should contain only the title, thereby facilitating anonymous reviewing. The authors' details should be supplied on a separate page and the author for correspondence should be identified clearly, along with full contact details, including e-mail address.

Running Title: A short title of not more than fifty characters, including spaces, should be provided.

Keywords: Up to six key words to aid indexing should also be provided.

Main Text: All papers should have a structured abstract (maximum 150 words) as follows: Background, Method, Results, and Conclusions. The abstract should provide an outline of the research questions, the design, essential findings and main conclusions of the study. Authors should make use of headings within the main paper as follows: Introduction, Method, Results and Discussion. Subheadings can be used as appropriate. All authors must clearly state their research questions, aims or hypotheses clearly at the end of the Introduction. Figures and Tables should be submitted as a separate file.

Style: Manuscripts should be formatted with a wide margin and double spaced. Include all parts of the text of the paper in a single file, but do not embed figures. Please note the following points which will help us to process your manuscript successfully:

-Include all figure legends, and tables with their legends if available.

-Do not use the carriage return (enter) at the end of lines within a paragraph.

-Turn the hyphenation option off.

-In the cover email, specify any special characters used to represent non-keyboard characters.

-Take care not to use l (ell) for 1 (one), O (capital o) for 0 (zero) or ß (German esszett) for (beta).

-Use a tab, not spaces, to separate data points in tables.

-If you use a table editor function, ensure that each data point is contained within a unique cell, i.e. do not use carriage returns within cells.

Spelling should conform to *The Concise Oxford Dictionary of Current English* and units of measurements, symbols and abbreviations with those in *Units, Symbols and Abbreviations* (1977) published and supplied by the Royal Society of Medicine, 1 Wimpole Street, London W1M 8AE. This specifies the use of S.I. units.

6.3 References

APA - American Psychological Association

References should be prepared according to the Publication Manual of the American Psychological Association (6th edition). This means in text citations should follow the author-date method whereby the author's last name and the year of publication for the source should appear in the text, for example, (Jones, 1998). The complete reference list should appear alphabetically by name at the end of the paper.

A sample of the most common entries in reference lists appears below. Please note that a DOI should be provided for all references where available. For more information about APA referencing style, please refer to the [APA FAQ](#). Please note that for journal articles, issue numbers are not included unless each issue in the volume begins with page one.

Journal article

Example of reference with 2 to 7 authors

Beers, S. R. , & De Bellis, M. D. (2002). Neuropsychological function in children with maltreatment-related posttraumatic stress disorder. *The American Journal of Psychiatry*, 159, 483–486. doi:10.1176/appi.ajp.159.3.483

Ramus, F., Rosen, S., Dakin, S. C., Day, B. L., Castellote, J. M., White, S., & Frith, U. (2003). Theories of developmental dyslexia: Insights from a multiple case study of dyslexic adults. *Brain*, 126(4), 841-865. doi: 10.1093/brain/awg076

Example of reference with more than 7 authors

Rutter, M., Caspi, A., Fergusson, D., Horwood, L. J., Goodman, R., Maughan, B., ... Carroll, J. (2004). Sex differences in developmental reading disability: New findings from 4 epidemiological studies. *Journal of the American Medical Association*, 291(16), 2007-2012. doi 10.1001/jama.291.16.2007

Book Edition

Bradley-Johnson, S. (1994). Psychoeducational assessment of students who are visually impaired or blind: Infancy through high school (2nd ed.). Austin, TX: Pro-ed.

6.4 Tables, Figures and Figure Legends

Tables should include only essential data. Each table must be typewritten on a separate sheet and should be numbered consecutively with Arabic numerals, e.g. Table 1, and given a short caption.

Figures should be referred to in the text as Figures using Arabic numbers, e.g. Fig.1, Fig.2 etc, in order of appearance. Figures should be clearly labelled with the name of the first author, and the appropriate number. Each figure should have a separate legend; these should be grouped on a separate page at the end of the manuscript. All symbols and abbreviations should be clearly explained. In the full-text online edition of the journal, figure legends may be truncated in abbreviated links to the full screen version. Therefore, the first 100 characters of any legend should inform the reader of key aspects of the figure.

Preparation of Electronic Figures for Publication

Although low quality images are adequate for review purposes, print publication requires high quality images to prevent the final product being blurred or fuzzy. Submit EPS (line art) or TIFF (halftone/photographs) files only. MS PowerPoint and Word Graphics are unsuitable for printed pictures. Do not use pixel-oriented programmes. Scans (TIFF only) should have a resolution of at least 300 dpi (halftone) or 600 to 1200 dpi (line drawings) in relation to the reproduction size. Please submit the data for figures in black and white or submit a Colour Work Agreement Form. EPS files should be saved with fonts embedded (and with a TIFF preview if possible).

Further information can be obtained at Wiley-Blackwell's guidelines for figures: <http://authorservices.wiley.com/bauthor/illustration.asp>.

Check your electronic artwork before submitting it: <http://authorservices.wiley.com/bauthor/eachecklist.asp>.

Permissions: If all or parts of previously published illustrations are used, permission must be obtained from the copyright holder concerned. It is the author's responsibility to obtain these in writing and provide copies to the Publisher.

Colour Charges: It is the policy of the *Journal of Applied Research in Intellectual Disabilities* for authors to pay the full cost for the reproduction of their colour artwork. Colour Work Agreement Form can be downloaded [here](#).

7. AFTER ACCEPTANCE

Upon acceptance of a paper for publication, the manuscript will be forwarded to the Production Editor who is responsible for the production of the journal.

7.1 Proof Corrections

The corresponding author will receive an e-mail alert containing a link to a website. A working e-mail address must therefore be provided for the corresponding author. The proof can be downloaded as a PDF file from this site.

Acrobat Reader will be required in order to read this file. This software can be downloaded (free of charge) from the following website:

www.adobe.com/products/acrobat/readstep2.html

This will enable the file to be opened, read on screen, and printed out in order for any corrections to be added. Further instructions will be sent with the proof. Proofs will be posted if no e-mail address is available; in your absence, please arrange for a colleague to access your e-mail to retrieve the proofs.

Proofs must be returned to the Production Editor within 3 days of receipt.

As changes to proofs are costly, we ask that you only correct typesetting errors. Excessive changes made by the author in the proofs, excluding typesetting errors, will be charged separately. Other than in exceptional circumstances, all illustrations are retained by the Publisher. Please note that the author is responsible for all statements made in their work, including changes made by the copy editor.

7.2 Early View (Publication Prior to Print)

The *Journal of Applied Research in Intellectual Disabilities* is covered by Wiley-Blackwell's Early View service. Early View articles are complete full-text articles published online in advance of their publication in a printed issue. Early View articles are complete and final. They have been fully reviewed, revised and edited for publication, and the authors' final corrections have been incorporated. Because they are in final form, no changes can be made after online publication. The nature of Early View articles means that they do not yet have a volume, issue or page number, so Early View articles cannot be cited in the traditional way. They are therefore given a DOI (digital object identifier) which allows the article to be cited and tracked before it is allocated to an issue. After print publication, the DOI remains valid and can continue to be used to cite and access the article.

7.3 Author Services

Online production tracking is available for your article through Wiley-Blackwell's Author Services. Author Services enables authors to track their article - once it has been accepted - through the production process to publication online and in print. Authors can check the status of their articles online and choose to receive automated e-mails at key stages of production. The author will receive an e-mail with a unique link that enables them to register and have their article automatically added to the system. Please ensure that a complete e-mail address is provided when submitting the manuscript.

Visit <http://authorservices.wiley.com/bauthor/> for more details on online production tracking and for a wealth of resources include FAQs and tips on article preparation, submission and more.

For more substantial information on the services provided for authors, please see Wiley-Blackwell's Author Services.

7.4 Author Material Archive Policy

Please note that unless specifically requested, Wiley-Blackwell will dispose of all hardcopy or electronic material submitted two issues after publication. If you require the return of any material submitted, please inform the editorial office or Production Editor as soon as possible.

7.5 Offprints and Extra Copies

Free access to the final PDF offprint of the article will be available via Author Services only. Additional paper offprints may be ordered online. Please click on the following link, fill in the necessary details and ensure that you type information in all of the required fields:
<http://offprint.cosprinters.com/blackwell>

If you have queries about offprints please email offprint@cosprinters.com

7.6 Video Abstracts

Bring your research to life by creating a video abstract for your article! Wiley partners with Research Square to offer a service of professionally produced video abstracts. Learn more about video abstracts at www.wileyauthors.com/videoabstracts and purchase one for your article at <https://www.researchsquare.com/wiley/> or through your Author Services Dashboard. If you have any questions, please direct them to videoabstracts@wiley.com.

Appendix E. Semi-Structured Interview
**Staffordshire University Professional Doctorate in
Clinical Psychology**

School of Life Sciences and Education, Staffordshire University,
Leek Road, Stoke-on-Trent ST4 2DF E DClInPsy@staffs.ac.uk T
+44 (0)1782 294007



Semi-Structured Interview

The interview questions will be informed by the focus group; therefore, these questions may change or be altered based on the focus group feedback. The order of these questions may also change based on the direction the participant takes the conversation.

Questions asked will relate to the main aim of the research; *This study aims to investigate how support workers, who are working in communal supported living accommodation for adults with learning disabilities, understand their role in facilitating access to the internet in the pursuit of personal and sexual relationships, for the people they support.*

- Could you tell me about how you understand your role, in general, as a support worker?
 - What expectations are there for how you support people within your role?
 - What about in terms of supporting people with their personal and sexual relationships?
 - Accessing the internet is becoming part of everyday life for people; how do you understand your role in supporting people to access the internet?
 - Are there any barriers to supporting people to access the internet that you encounter?
 - 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?

- Have you given this support before?
- Did you feel it was part of your role?
- How did it go?
- What difficulties might you/did you face when trying to support people to access these websites/apps?
- 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?
 - 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?
 - Does your organisation 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?
 - 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

Appendix F. Focus Group Organisational Sourcing Letter

Staffordshire University Professional Doctorate in Clinical Psychology
School of Life Sciences and Education, Staffordshire University,
Leek Road, Stoke-on-Trent ST4 2DF E DClinPsy@staffs.ac.uk T +44 (0)1782 294007



Dear Organisation/Group,

Accessible Summary

- My name is Jason Lines, a Trainee Clinical Psychologist studying at Staffordshire University.
- I want to conduct some research about how Support Workers see their role in helping adults with a learning disability use the internet.
- I am really interested in how those Support Workers see their role in supporting adults with a learning disability to use the internet for personal and sexual relationships.
- I am also really interested in those adults with a learning disability who live in a group home with others, rather than on their own or with family.
- Before I start my research, I want to ask your organisation/group what you think about my research and what you think might be good questions to ask those Support Workers who are taking part.
- I would like to come and meet you all as a group to do this.

Other information

I am currently studying at Staffordshire University on the Professional Doctorate in Clinical Psychology programme. I am also employed by the South Staffordshire and Shropshire NHS Trust as a Trainee Clinical Psychologist.

As part of my studies, I have been tasked with completing a piece of clinically relevant research, which is the reason why I am contacting you.

The piece of research I would like to complete is titled: *"Internet Access for Sexual Relations? Not sure about that!" Investigating the attitudes of support workers in communal supported living settings, in regards to accessing the internet for personal and sexual relations of the adults with learning disabilities whom they support.*

In order to complete this piece of research, I would first like to hold a focus group, with the purposes of discussing my research idea and thinking about the questions I might ask support workers in the interviews.

I would be extremely grateful if you, and those currently attending your group/organisation, would be willing to join the focus group to discuss my research at a time and date convenient for you all.

Kind regards,

Jason Lines
Trainee Clinical Psychologist
Staffordshire University

Appendix G. Focus Group Participant Information Sheet
**Staffordshire University Professional Doctorate in
Clinical Psychology**

School of Life Sciences and Education, Staffordshire
University,
Leek Road, Stoke-on-Trent ST4 2DF E
DClinPsy@staffs.ac.uk T +44 (0)1782 294007



Focus Group Participant Information Sheet

- My name is Jason Lines, a Trainee Clinical Psychologist studying at Staffordshire University.
- I would like to ask you about some interview questions that I hope to use in a research study.
- My research is looking at how support workers understand their role in supporting adults with a learning disability to access the internet.
 - Specifically, support to access the internet for personal and sexual relationships.
- I want to know what you think about my interview questions.
- I also want to know if you think there are questions I should ask, that I have not thought of.
- If you participate in this focus group – you would be asked to sit with me and a few other people who are also joining the focus group, to talk about the interview questions for around an hour.
 - It is possible that participation in this focus group may cause some emotional distress and anxiety for some participants.
 - Some people might find it difficult talking about things such as personal and sexual relationships.
 - You have the right to withdraw at any time.
- Your contribution to this research will help to shape the interview questions, enabling me and the participants to have a conversation which generates data as rich as possible.

- This research will hopefully improve the lives of Adults with a learning disability who are looking to access the internet with support, for the purposes of personal and sexual relationships. It may do this by encouraging organisations who provide support for adults with learning disabilities, to consider their policies, guidelines, and training for this matter.

Additional Information

Researcher

My name is Jason Lines, a student at Staffordshire University studying the Professional Doctorate in Clinical Psychology. I am also employed by South Staffordshire and Shropshire NHS Trust as a Trainee Clinical Psychologist.

Contact information

Jason Lines email address - **1025077g@student.staffs.ac.uk**

What would participating involve?

Participation for you would involve the following steps;

- Sitting in a focus group of between 4-7 individuals, including myself.
- Discussing the interview questions.
- Giving feedback on the questions, if you want to.
- Suggesting other questions which may not have been considered, if you want to.
- Taking part for between 45-60 minutes.

What are the possible benefits of participating in the focus group?

- It allows you to hear research interview questions before they are put into practice.
- It gives you a chance to have an impact on the direct and shape of this research piece.
- If you are passionate about this area, it offers a platform to add questions which you feel are relevant.

What are the possible risks or disadvantages of taking part?

- Some people find it hard talking about difficult topics.
- You might feel uncomfortable with some of the topics.
- It may bring up memories for you, if you have experienced difficulties in this area before.

What can you do if you are distressed?

- You can take your time and pause if you need to.
- You can bring a drink in with you.
- You can ask for a short break.

- You can refrain from answering specific questions if you choose, we will move on without penalty.
- You can leave at **any point** and ask to withdraw.

Remember

- If you participate, you will **not** be identifiable in the write up or publication.

What if something goes wrong or I want to withdraw?

Please email me and we can have a chat about it. Or, if you wish to withdraw without a chat, that is OK too.

What happens if I withdraw?

- All your information will be destroyed securely, and you will not be contacted again.

What happens when this study is finished?

- Hopefully, it will be published in a relevant journal to inform future research and future practices.
- If you want a copy, please email me and I will email it to you as soon as possible.

What if I have other questions?

Please email me - I will be more than happy to answer any question as soon as I can.

What next?

If you wish to participate - that's great, **thank you**. Please contact me on the email provided;

Jason Lines - **I025077g@student.staffs.ac.uk**

If you are part of a group or organisation, they can email me to confirm too if you would prefer.

If you do not wish to participate, that's fine, thank you for taking the time to read this.

Appendix H. Focus Group Consent Form
Staffordshire University Professional Doctorate in Clinical Psychology

School of Life Sciences and Education, Staffordshire University,
Leek Road, Stoke-on-Trent ST4 2DF E
DClinPsy@staffs.ac.uk T +44 (0)1782 294007



Focus Group Participant Consent Form

Focus Group Purpose:

To discuss the interview questions which have been proposed for the below study/project.

Title of Project:

Investigating how support workers in communal settings for adults with learning disabilities understand their role in facilitating access to the internet for personal and sexual relationships.

Name of Researcher:

Jason Lines

Please initial box

1. I confirm that I have read the Focus Group Participant Information Sheet dated 23/10/2017 (version one) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
3. I understand that the information collected will be used to support other research in the future, and may be shared anonymously with other researchers.
4. I understand all data will be stored safely on password protected

computer systems, or locked away securely if any paper data is generated, for 10 years before it is destroyed.

5. I understand that information gathered at this focus group may be used to change or adjust research interview questions. And that new questions may be generated from the focus group.

6. I understand I will not be identifiable in any write up or publication.

7. I agree to take part in the above study.

Name of Participant Date Signature

Name of Person Date Signature
taking consent

Appendix I. Sourcing Organisations for Support Workers to Interview

Staffordshire University Professional Doctorate in Clinical Psychology
School of Life Sciences and Education, Staffordshire University,
Leek Road, Stoke-on-Trent ST4 2DF E DClintPsy@staffs.ac.uk T +44 (0)1782 294007



Dear Organisation,

My name is Jason Lines, a student studying at Staffordshire University on the Professional Doctorate in Clinical Psychology programme. I am also employed by the South Staffordshire and Shropshire NHS Trust as a Trainee Clinical Psychologist.

As part of my studies, I have been tasked with completing a piece of clinically relevant research, which is the reason why I am contacting you.

The piece of research I would like to complete is titled: *"Investigating how support workers in communal settings for adults with learning disabilities understand their role in facilitating access to the internet for personal and sexual relationships."*

In order to complete this research, I need to interview support workers currently working within communal supported living settings for adults with learning disabilities. Your organisation runs services such as these within Staffordshire and Shropshire, and if possible, I would like to approach those services in order to acquire participants for my study.

I would be extremely grateful if you, and those individuals currently living at your services, would be willing to allow me to recruit support workers and interview them for the purposes of this study.

Please see the attached Participant Information Sheet for further information.

Kind regards,

Jason Lines
Trainee Clinical Psychologist
Staffordshire University

Appendix J. Support Worker Interviews Participant Information Sheet
Staffordshire University Professional Doctorate in
Clinical Psychology

School of Life Sciences and Education, Staffordshire
University,
Leek Road, Stoke-on-Trent ST4 2DF E
DClinPsy@staffs.ac.uk T +44 (0)1782 294007



Participant Information Sheet

Summary

- My name is Jason Lines, a Trainee Clinical Psychologist studying at Staffordshire University.
- I want to conduct some research about how Support Workers see their role in helping adults with a learning disability use the internet.
- I am really interested in how those Support Workers understand their role in supporting adults with a learning disability to use the internet for personal and sexual relationships.
- I am also really interested in the views of Support Workers who work with adults with a learning disability who live in a group home with others, rather than on their own or with family.
- If you participate in my study – you would be involved in an interview, it would last around an hour.
 - I would be asking questions about your views on helping the people you support to use the internet for personal and sexual relationships.
 - It is possible that participation in this study may cause some emotional distress and anxiety for some participants.
 - You have the right to withdraw at any time and have your data deleted, if you participate.
 - The interview data will be kept, however, if you withdraw after four weeks from when the interview takes place.

- This research will hopefully help to improve the lives of the people you support, by encouraging organisations who provide support for adults with learning disabilities, to consider their policies, guidelines, and training for this matter.

Study Title

"Investigating how support workers in communal settings for adults with learning disabilities understand their role in facilitating access to the internet for personal and sexual relationships."

Invitation

- You are invited to take part in a study.
- This study is looking to recruit support workers and interview them.
- The interview is looking to find out about how you understand your role of supporting people with a learning disability to access the internet, in the pursuit of sexual and personal relationships.

Researcher

My name is Jason Lines, a student at Staffordshire University studying the Professional Doctorate in Clinical Psychology. I am also employed by the South Staffordshire and Shropshire NHS Trust as a Trainee Clinical Psychologist.

Contact information

Jason Lines email address - l025077g@student.staffs.ac.uk

What is the study?

I am investigating how support workers, who work where adults with learning disabilities live with support, understand their role in supporting access to the internet for the people they support. Specifically, supporting access to internet sites for sexual and personal relationships.

I plan to interview between 10-12 support workers in the Staffordshire and Shropshire area.

The interview's will be turned into a text document on the computer and I will be analysing that to look for themes.

Criteria for participating

- Paid support worker, with at least one years' experience.
- Working in a communal supported living home or residential care home for adults with learning disabilities.
- Within the Staffordshire and Shropshire area.

What would participating involve?

Participation for you would involve the following steps;

- Contacting the researcher to agree to participate.
- Arranging a suitable venue for the interview to take place.
- Signing a consent form.
- Taking part in an interview for between 45-60 minutes.

What are the possible benefits for participating in this study?

- It gives you an opportunity to speak about an important subject for some people.
- It allows you to speak about how you understand your own role in providing support to adults with learning disabilities to someone outside of your organisation.
- The findings of this study will hopefully help make positive changes in policy making for organisations who support adults with disabilities, regarding accessing the internet for personal and sexual relationships.
- The findings from this study may open other avenues for other research.

What are the possible risks or disadvantages of taking part?

- Some people find it hard talking about difficult topics.
- You might feel uncomfortable with some of the topics.
- There might be specific questions you do not wish to answer, which is ok.

What can you do?

- You can take your time and pause if you need to.
- You can bring a drink in with you.
- You can ask for a short break.
- You can refrain from answering specific questions if you choose, we will move on without penalty.
- You can end the interview at **any point** and ask to withdraw.

Remember

- All efforts are made to anonymise the data and ensure confidentiality.
- If you participate, you will **not** be identifiable in the write up or publication.

Other supporting information

What if I need to contact someone after the interview, if I have some adverse effects?
Or feel like I need further debriefing?

Please contact the researcher as the first point of call on the email address outlined.

What if something goes wrong or I want to withdraw?

Please email me and we can have a chat about it. Or, if you wish to withdraw and have your data deleted without a chat, that is OK too.

What happens if I withdraw?

- All your information will be destroyed securely and you will not be contacted again.
- However, if you have an interview and four weeks pass, your interview data will still be used.

What happens when this study is finished?

- Hopefully, it will be published in a relevant journal to inform future research and future practices.
- If you want a copy, please email me and I will email it to you as soon as possible.

What if I have other questions?

Please email me - I will be more than happy to answer any question as soon as I can.

What next?

If you wish to participate - that's great, **thank you**. Please contact me on the email provided;

Jason Lines - **l025077g@student.staffs.ac.uk**

If you do not wish to participate, that's fine, thank you for taking the time to read this.

Appendix K. Interview Consent Forms

Staffordshire University Professional Doctorate in Clinical Psychology

School of Life Sciences and Education, Staffordshire University,
Leek Road, Stoke-on-Trent ST4 2DF E
DClinPsy@staffs.ac.uk T +44 (0)1782 294007



Participant Identification Number for this trial:

CONSENT FORM

Title of Project: *"Investigating how support workers in communal settings for adults with learning disabilities understand their role in facilitating access to the internet for personal and sexual relationships."*

Name of Researcher: Jason Lines

Please initial box

1. I confirm that I have read the Participant Information Sheet dated 01/06/2017 (version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

3. I understand that my data will be used in the write up and analysis of this study, which may appear in research publications, be mentioned at conferences, or be used in teaching.

- 4. I understand that I will not be identifiable in the write up and publication of this research.
- 5. I understand that data collected will be stored securely on password protected computer systems and hard data will be locked away securely at Staffordshire University.
- 6. I understand that data will be destroyed after 10 years.
- 7. I understand my right to withdraw at any time.
- 8. I understand my right to have my interview data deleted, within four weeks following the interview.
- 9. I agree to take part in the above study.

_____	_____	_____
Name of Participant	Date	Signature

Jason Lines

_____	_____	_____
Name of Person	Date	Signature

taking consent

Appendix L. Interview Participant Demographic Forms
Staffordshire University Professional Doctorate in
Clinical Psychology

School of Life Sciences and Education, Staffordshire
University,
Leek Road, Stoke-on-Trent ST4 2DF E
DClinPsy@staffs.ac.uk T +44 (0)1782 294007



Demographic Information

Participant

Age:	
Gender:	
Years working as a support worker:	
Number of hours working as a support worker per week:	

Researcher

Participant Identification Number:

Appendix M. Interview Debrief Forms

Staffordshire University Professional Doctorate in Clinical Psychology

School of Life Sciences and Education, Staffordshire University,
Leek Road, Stoke-on-Trent ST4 2DF E
DClinPsy@staffs.ac.uk T +44 (0)1782 294007



Debrief

Thank you for participating in this study.

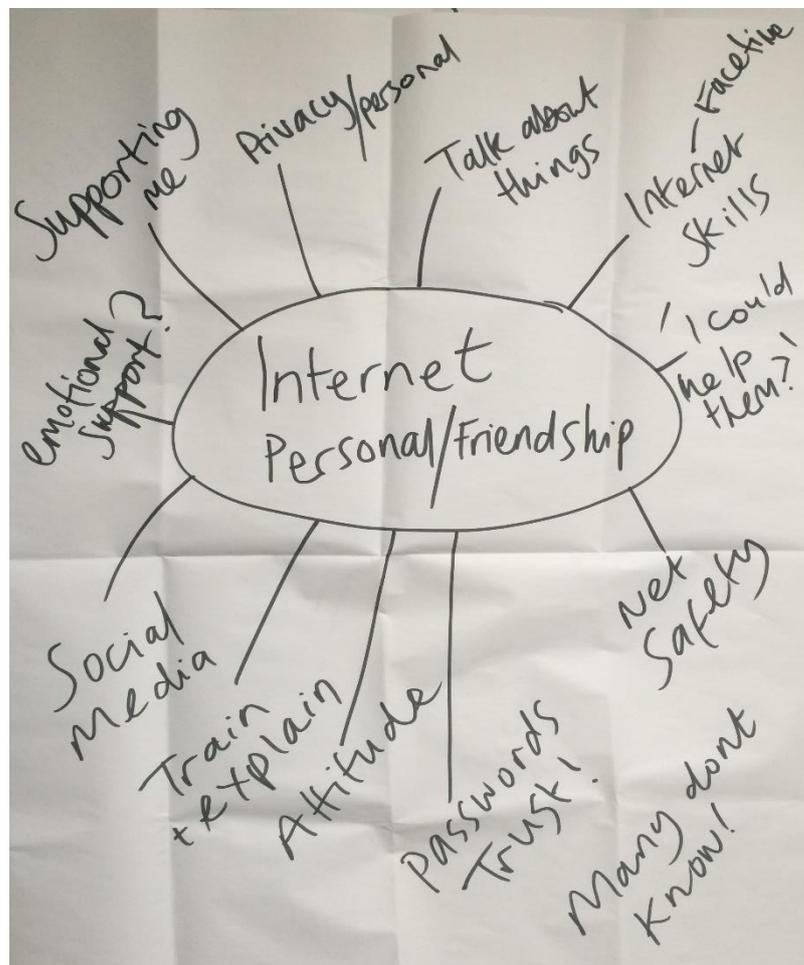
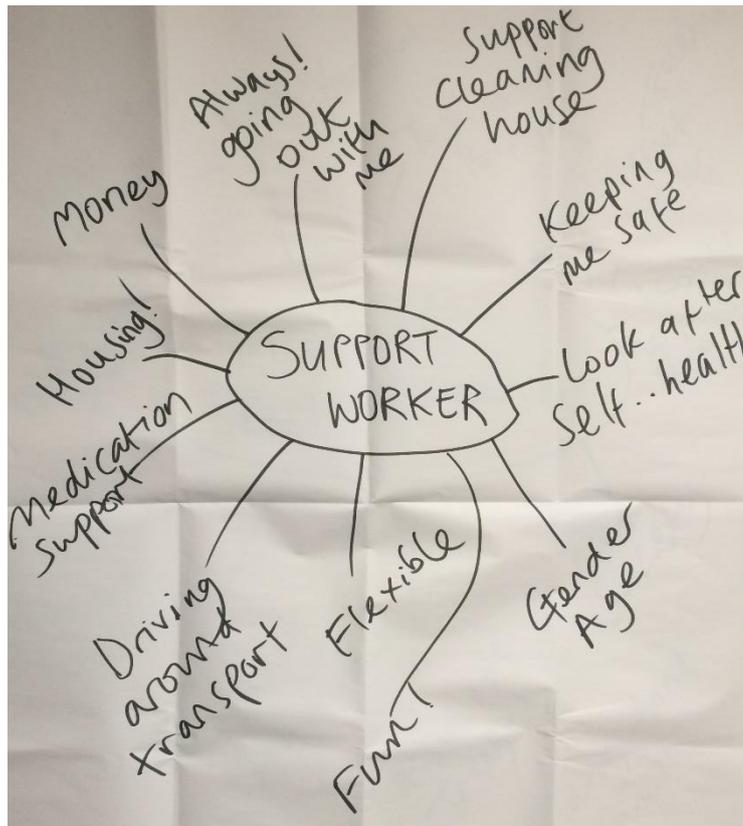
As was outlined in the Participant Information Sheet - this interview data will be transferred to a secure USB stick.

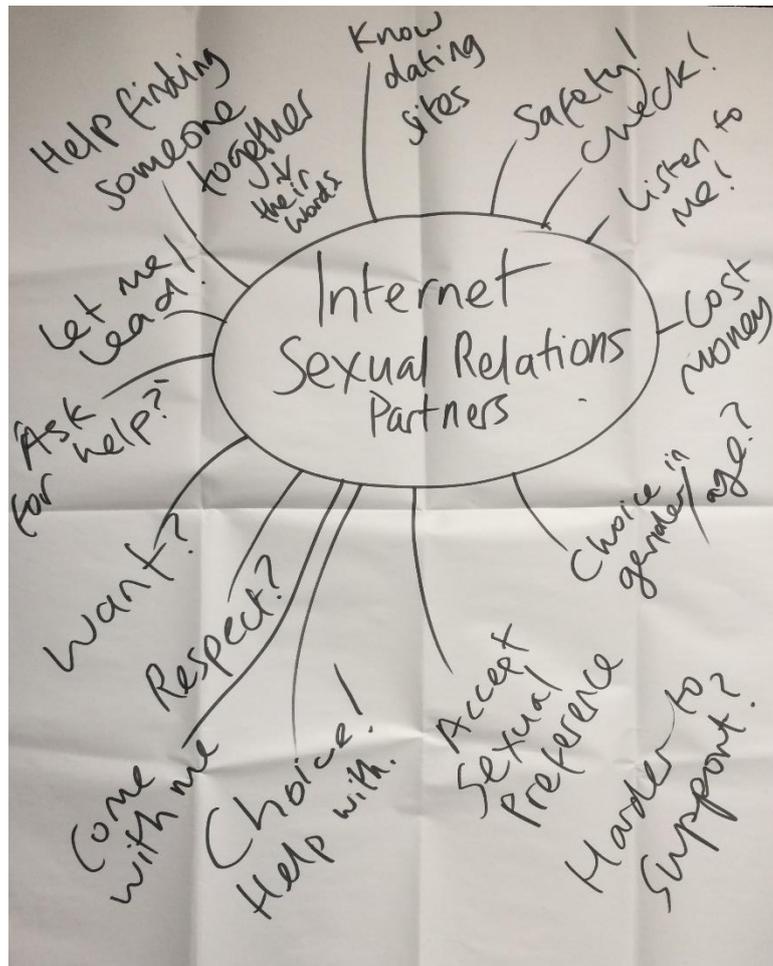
If, within the next four weeks, you wish to withdraw from this study, you can contact me on the email address below to request that your data be destroyed.

Researcher contact details:

Jason Lines - **l025077g@student.staffs.ac.uk**

Appendix N. Outcomes from Focus Group





These images show the flip chart sheets which were used to facilitate and record discussion within the focus group, when the research topic was discussed broadly. These maps helped to shape and define the semi-structured interview schedule.

Appendix O. Ethical Approval



ETHICAL APPROVAL FEEDBACK

Researcher name:	Jason Lines
Title of Study:	Investigating how support workers in communal settings for adults with learning disabilities understand their role in facilitating access to the internet for personal and sexual relationships
Status of approval:	Approved

Thank you for addressing the committee's comments. Your research proposal has now been approved by the Ethics Panel and you may commence the implementation phase of your study. You should note that any divergence from the approved procedures and research method will invalidate any insurance and liability cover from the University. You should, therefore, notify the Panel of any significant divergence from this approved proposal.

You should arrange to meet with your supervisor for support during the process of completing your study and writing your dissertation.

When your study is complete, please send the ethics committee an end of study report. A template can be found on the ethics BlackBoard site.

A handwritten signature in black ink, appearing to read 'R. Naemi'.

Signed: Dr Roozbeh Naemi

Date:

Chair of the Health Sciences Ethics Panel

18.12.2017

Appendix P. Reflective Statement

The researcher is a 34-year-old, white British male, currently employed in the NHS as a Trainee Clinical Psychologist. The researcher has specific interests in learning disability services as much of their experience comes from these settings. These experiences include time as a support worker in a communal setting for adults with learning disabilities, a year as an Assistant Psychologist in a Community Learning Disabilities Team, and a second-year doctoral placement in a Community Learning Disabilities team.

The researcher has strong beliefs in the rights of people with learning disabilities and attempted to keep this in mind when analysing the data, to ensure that it did not unduly influence theme generation. The researcher made use of the qualitative researcher groups at the university, which included tutors and peers, to discuss how themes were generated and confirm that the themes were a reasonable conclusion based on the data.

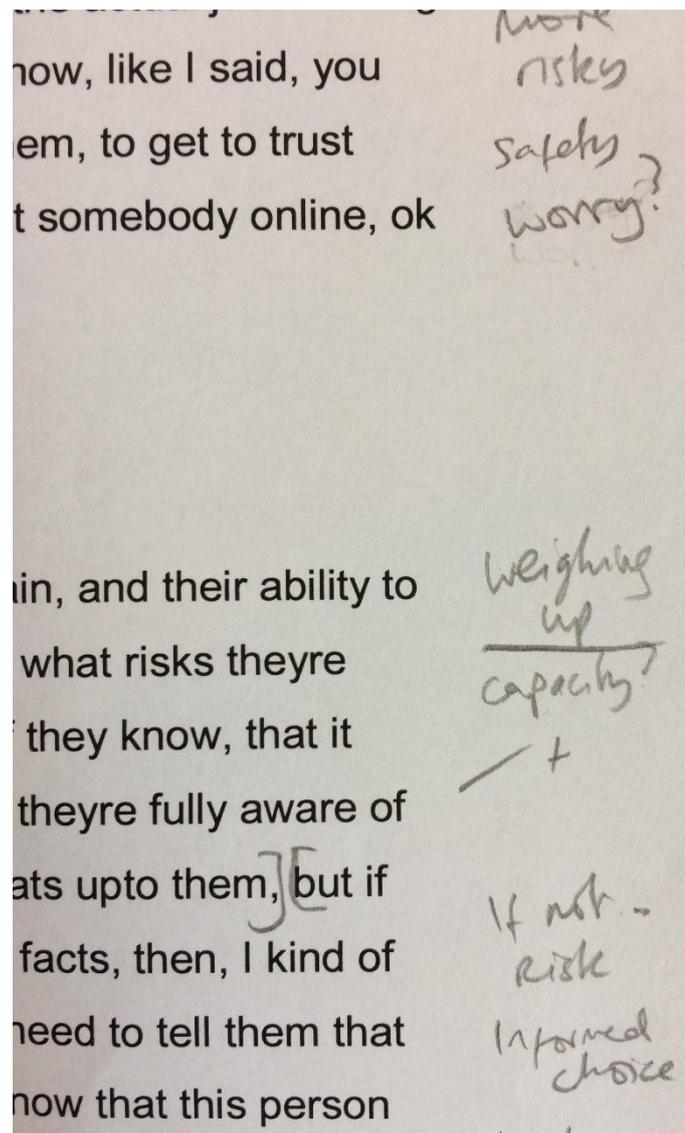
The researcher was aware of the potential power imbalances between a Trainee Clinical Psychologist and a support worker, particularly as support services are often in close contact with local CLDT's. It is difficult to know how much this influenced the direction of the interviews, but efforts were made to make the support workers feel at ease, such as not wearing an NHS badge, and dressing more casually.

Preconceptions were identified within a reflexive journal maintained during the research process, one main assumption that the researcher noted before the research began, was a sense that adults with learning disabilities are not well supported when it comes to internet use. These preconceptions came from previous experiences, it was an important to note them, particularly during creation of the interview schedule, and during analysis.

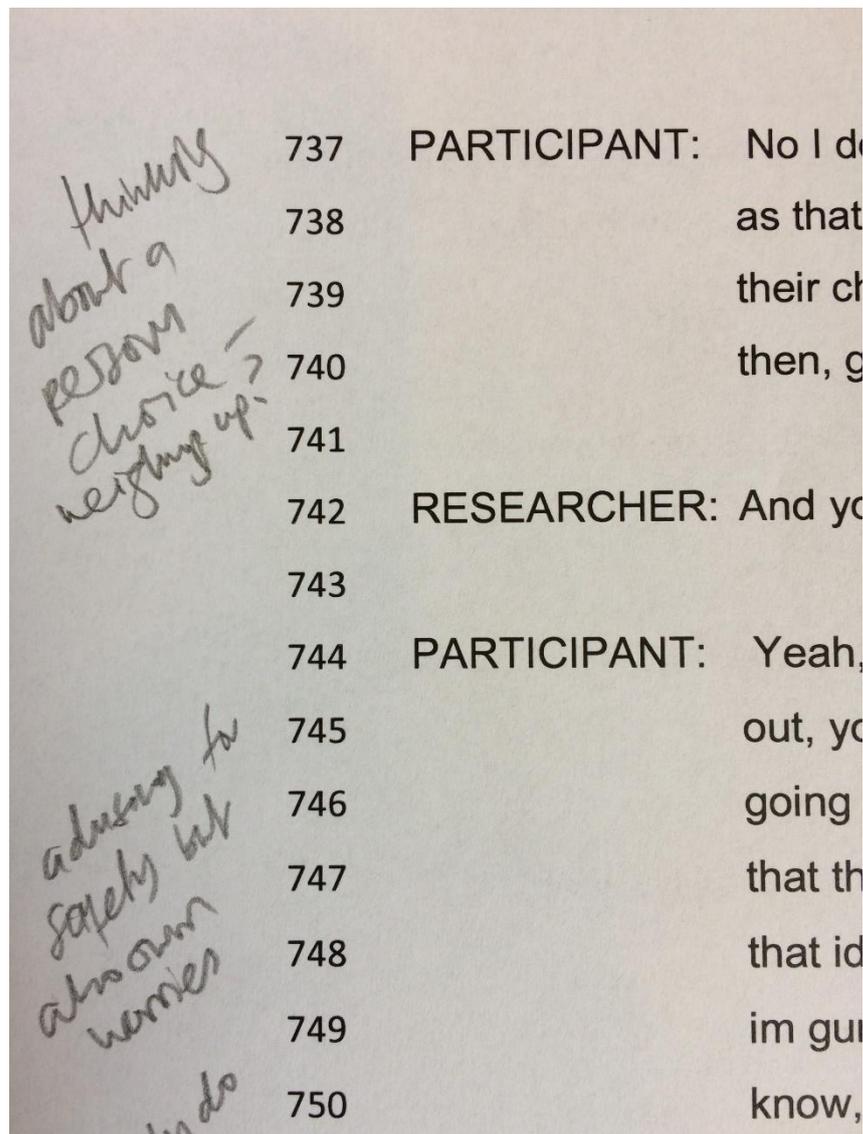
Appendix Q. Thematic Analysis Process

<p>thinking about a person's choice weighing up?</p>	<p>737 738 739 740 741</p>	<p>PARTICIPANT: No I don't think so, I think it's just, like I said you know, [as long as that person is aware of good points, bad points, then, it's their choice to make, you know if they're happy to take the risk, then, good luck to them.]</p>	<p>providing awareness advising person's choice</p>
	<p>742</p>	<p>RESEARCHER: And your role in that is to provide information?</p>	
<p>advising to safety but about own worries</p>	<p>743 744 745 746 747 748 749 750 751 752 753 754 755</p>	<p>PARTICIPANT: Yeah, I'd always make sure that, you know, if they were going out, you know I would, [I mean if they don't tell me where they're going then that's up to them, but you know I'd try and make sure that there was a rough time that they were going to be back, or that I'd get, or I'd say could you ring me every couple of hours or I'm gonna panic.] you know [I'd make sure that they knew you know, they did know that this person might not be genuine, you know they might not just be looking to meet for a coffee type of thing, but if they then went on and wanted to take the risk after I had informed them of the risk, then that's, their decision to make.]</p>	<p>advising panic/worry their choice informed decisions Risk advising</p>
<p>Can only do so much? advise + warn but hesitation</p>	<p>756 757 758 759</p>	<p>RESEARCHER: So I guess my last question in regards to that is, if they did choose to take a risk, and it didn't go so well, what would you be doing then?</p>	
<p>discussing at all times important</p>	<p>760 761 762 763 764 765 766 767</p>	<p>PARTICIPANT: [Then I'd probably, we'd probably have the conversation of, has it put you off doing it again you know, is there things that you think you did wrong that maybe you could maybe next time,] [you know next time, if you're meeting somebody for the first time, you know if you let us know, there's no reason that a staff member can't go with you, you know, and even observe from a distance type of thing, the person that your meeting doesn't even have to know somebody is with you.] you know, we can</p>	<p>conversation about difference weighing up risk + options options</p>
<p>trying to advise plus offer guidance with safety + risk considered</p>			

General notes and thoughts written onto the transcripts on the left.



The beginnings of codes and theme ideas on the right. This image is zoomed in to show details.



An example of notes and thoughts written on the left side of each transcript.

Participants and Coding - Saved

File Home Insert Page Layout Formulas Data Review View Help Tell me what you want to do

Clipboard Font Alignment Number Styles Cells Editing

Q4

	Identified Code								
	Transcript 1	Transcript 2	Transcript 3	Transcript 4	Transcript 5	Transcript 6	Transcript 7		
	Code	Code	Code	Code	Code	Code	Code	Code	Code
5	Advise	Above and beyond	Above and beyond	Advising	Advising	Advising	Advising	Advising	Advising
6	Awareness of danger	Beliefs and values	Advising	Appropriacy	Appropriacy	Beliefs and values	Awareness of danger	Beliefs and values	Beliefs and values
7	Beliefs and values	Care planning	Beliefs and values	Beliefs and values	Beliefs and values	Desire for training	Desire for training	Collaborative	Collaborative
8	Best interests	Desire for training	Best interests	Best interests	Care planning	Do they have capacity	Desire for training	Consent	Consent
9	Care planning	Do they have capacity	Collaborative	Care planning	Desire for training	Feels awkward	Direct intervention	Dangers of int	Dangers of int
10	Do they have capacity	Education	Desire for training	Communication difficulties	Education	Feels uncomfortable	Do they have capacity	Desire for trai	Desire for trai
11	Education	Empowering them	Education	Desire for training	Expected to know	Guided support	Education	Direct interve	Direct interve
12	Encouragement	External professionals	Experience	Do they have capacity	Experience	Internet dangers	Feels awkward	Do they have	Do they have
13	Everyones safety	Feels awkward	Feel anxious	Education	Feel confident	Lack of personal experience	Guided support	Education	Education
14	Expected to deal with it	Feels frustrating	Feel nervous	Environment	Guided support	Lack of training	Have capacity	Encouraging	Encouraging
15	Experience	Feels uncomfortable	Feels awkward	Everyones safety	Internet dangers	Limitations in role	Internet dangers	Everyones saf	Everyones saf
16	External professionals	Individualised approach	Flexible approach	Experience	Lack of control	No guidance	Keeping family informed	Expected to	Expected to
17	Family	Internet dangers	Guided support	Funding	Lack of training	Personal experience	Lack of control	Experience	Experience
18	Feels daunting	Internet extra to role	Internet dangers	Guided support	Limitations in role	Practical support	Monitoring	Feel uncomfo	Feel uncomfo
19	Feels frustrating	Lack of services	Lack of training	Internet dangers	Organisational support	Promoting independence	No guidance	Feels annoyin	Feels annoyin
20	Feels horrible	Lack of training	Limitations in role	Internet extra to role	Personal experience	Respecting privacy	Personal experience	Feels frustrati	Feels frustrati
21	Feels isolated	Limitations in role	No guidance	Lack of training	Physical presence	Risk	Physical dangers	Flexible appro	Flexible appro
22	Firefighting	Looking past the internet	Organisational support	Limitations in role	Powerless	Safety	Physical presence	Guided suppo	Guided suppo
23	Generic training	Low pay	Personal experience	Monitoring	Practical support	Senior support	Practical support	Have capacity	Have capacity
24	Guided support	No guidance	Physical presence	No guidance	Professional input vital	The unknown	Professional input vital	Internet dang	Internet dang
25	Have capacity	Physical presence	Practical support	Organisational pressure	Relationship importance	Uncertainty in role	Protective	Lack of contro	Lack of contro
26	Helpless	Practical support	Priorities	Organisational support	Respecting privacy	Weighing up	Risk	Lack of service	Lack of service
27	Internet dangers	Priorities	Professional input vital	Personal experience	Risk	Worry	Safety	Lack of trainin	Lack of trainin
28	Lack capacity	Professional input vital	Promoting independence	Physical presence	Senior support		Senior support	Limitations in	Limitations in
29	Lack of control	Promoting independence	Protecting	Powerless	Societal issues		Sexual for difficult	Managing fam	Managing fam
30	Limitations in role	Relationship importance	Relationship importance	Practical support	Support worker variance		Talking about it feels ok	Monitoring	Monitoring
31	Mental capacity act	Respecting privacy	Research	Professional input vital	Uncertainty in role		The unknown	No guidance	No guidance
32	My safety	Risk	Respecting privacy	Promoting independence	Weighing up		Wary of danger	Personal expe	Personal expe
33	No guidance	Societal issues	Risk	Respecting privacy	Within team support		Weighing up	Physical dang	Physical dang
34	Physical presence	Support worker variance	Safety	Risk	Worry		Worry	Physical suppo	Physical suppo
35	Positive risks	The unknown	Senior support	Risk positivity				Practical supp	Practical supp
36	Powerless	Weighing up	Should support everything	Safety				Professional i	Professional i
37	Problems arising		Societal issues	Support worker variance				Promoting inc	Promoting inc
38	Professional input vital		Support worker variance	The unknown				Relationship i	Relationship i

This is a screenshot of the excel file created which has all the transcripts and each code that occurred within the annotated transcript.

All codes found	
Advise AAU17ag	Were on the front line
Awareness of danger	Worry
Beliefs and values	Above and beyond
Best interests	* Desire for training
Care planning	* Empowering them
Do they have capacity	Feels awkward
Education	Feels uncomfortable
Encouragement	Individualised approach
Everyones safety	Internet extra to role
Expected to deal with it	in Lack of services
Experience	* Lack of training
External professionals	* Looking past the internet
Family	* Low pay
Feels daunting	* Practical support
Feels frustrating	Priorities
Feels horrible	Promoting independence
Feels isolated	Societal issues
Firefighting	Advising
Generic training	Collaborative
Guided support	Feel anxious
Have capacity	Feel nervous
Helpless	Flexible approach
Internet dangers	in Organisational support
Lack capacity	* Personal experience
lack of control	* Protecting
Limitations in role	* Research
Mental capacity act	Safety
My safety	Should support everything
No guidance	Appropriacy
Physical presence	Communication difficulties
Positive risks	Environment
Powerless	z Funding
Problems arising	Monitoring
Professional input vital	Organisational pressure
Putting in controls	Risk positivity positive risks
Relationship importance	z Within team support
Respecting privacy	Expected to know
Risk	Feel confident
Senior support	Uncertainty in role
Sexual relations more risky	Feels uncomfortable
Stuck	* Lack of personal experience
Support worker variance	* Direct intervention
The support line	Keeping family informed Family
The unknown	Physical dangers
Their safety	Protective protection
Warning signs	Sexual for difficult Sexual diff.
Weighing up	Talking about it feels ok -?
	Wary of danger
	Consent
	Dangers of internet / internal dangers
	Encouraging encouragement
	Expected to
	Feel uncomfortable
	Feels annoying
	Managing family family
	Physical danger
	* Physical support / practical supp?

weighing up
risk & safety
Capacity
External ^{seeking} support for support?
Advice + guidance + support
SW variance?
Beliefs + values
Experience

Expectations
weighing up ↔ Risk vs Safety
↓
Beliefs + values
↓
(SW variance) ↑ Experiences - z
Approach ↓ Support for Support
Expectations

↓

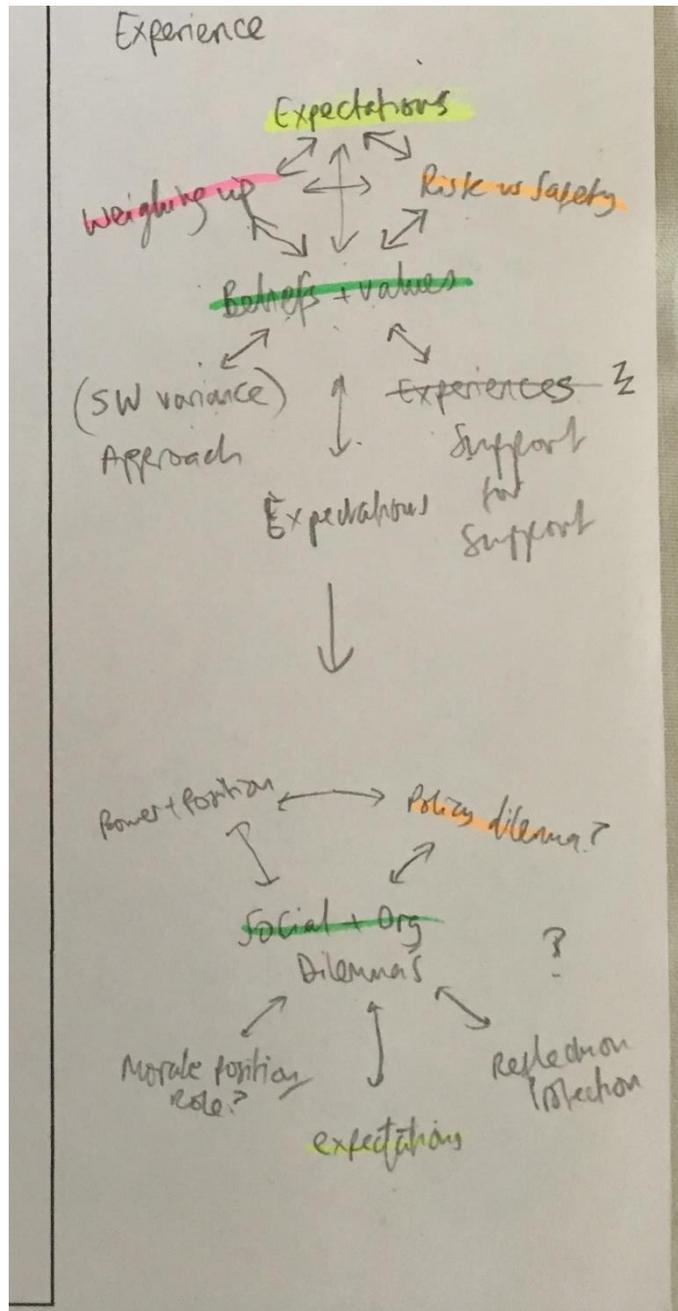
Power + Position → Policy dilemma?
↓
Social + Org dilemmas
↓
Moral position role? → expectations → Reflection / Action

This image shows the print out of all codes found within all the transcripts. On the left is the list and, on the right, the initial workings of a thematic map.

How ^{do} SW understand their role supporting ACD to

All codes found	
Advise Advising	Were on the front line
Awareness of danger	Worry
Beliefs and values	Above and beyond
Best interests	* Desire for training
Care planning	* Empowering them
Do they have capacity	Feels awkward
Education	Feels uncomfortable
Encouragement	Individualised approach
Everyones safety	Internet extra to role
Expected to deal with it	~ Lack of services
* Experience	* Lack of training
External professionals	Looking past the inter
Family	* Low pay
Feels daunting	* Practical support
Feels frustrating	Priorities
Feels horrible	Promoting independence
Feels isolated	Societal issues
Firefighting	Advising
* Generic training	Collaborative
Guided support	Feel anxious
Have capacity	Feel nervous
Helpless	Flexible approach
Internet dangers	~ Organisational support
Lack capacity	* Personal experience
Lack of control	Protecting
Limitations in role	* Research
Mental capacity act	Safety
	Should support every

A zoomed in image of the codes, colour coded to match the initial theme and thematic map ideas.



A zoomed in image of the initial stages of forming themes and the thematic map.