

Megan Montgomery. BSc Hons, MSc

A STUDY OF HOW PEOPLE WITH LEARNING DISABILITIES EXPERIENCE SOCIAL MEDIA

Section A: How People with Learning Disabilities Experience Social Media, a Literature Review

Word Count: 6447 (+160)

**Section B: A Grounded Theory of How People with Learning Disabilities Experience Social
Media**

Word Count: 7836 (+227)

Overall Word Count: 14,283 (+387)

A thesis submitted in partial fulfilment of the requirements of

Canterbury Christ Church University for the degree of

Doctor of Clinical Psychology

May 2022

SALOMONS INSTITUTE

CANTERBURY CHRIST CHURCH UNIVERSITY

Acknowledgements

I'd like to thank the people who gave their time to contribute to this project, including the people with learning disabilities and the support worker who facilitated their participation. Thank you to my two supervisors, friends and family for their support.

Summary of the major research project

Section A: This section provides a systematic review of literature regarding how people with learning disabilities experience social media. The 15 studies are discussed in terms of study characteristics, method and findings. Quality appraisal tools were used to critique the studies. The findings were grouped into three themes; feelings and attitudes towards social media, opportunities (sub-themes; independence and autonomy, developing and expressing identity, connection and belonging), challenges and support networks. Implications for clinical practice were discussed and included the need for clinicians to enquire about PWLD social media use as both a potential resource and contributing factor to distress. Recommendations for future research included the creation of a model of social media use, in order to further understand how people with learning disabilities experience social media.

Section B: This section presents a grounded theory study of interviews with people with learning disabilities who use social media. The data consisted of interviews with 11 individuals. A preliminary theoretical model is described, which suggests that people with learning disabilities face many opportunities and challenges when navigating the online world and that doing so leads to a sense of being seen online. This visibility poses opportunities for feelings of connection and belonging alongside increased exposure to disability stigma. Participants demonstrated a range of skills and attitudes in facing this stigma. Clinical and research implications are addressed.

Contents

Section A: Literature Review	1-36
Abstract.....	2
Introduction.....	3-6
Method.....	6-9
Findings.....	10-28
Study characteristics.....	10-16
Synthesis of findings.....	17-24
Quality appraisal.....	24-28
Discussion.....	28-30
References.....	30-36
Section B: Empirical Study	37-74
Abstract.....	38
Introduction.....	39-43
Rationale and aims.....	42-43
Method.....	43-49
Findings.....	49-62
Discussion.....	63-69
References.....	70-74
Section C: Appendices	75-111
Appendix 1. Qualitative Checklist, Critical Appraisal Skills Programme (2013).....	75-79
Appendix 2. Quality Assessment Tool for Before-After (Pre-Post) Studies	80-81
Appendix 3. Quality Assessment tool for Survey studies.....	82-83
Appendix 4. NIH Quality Assessment Tool for Cohort and Cross-Sectional Studies	84-85
Appendix 5. Accessible information sheet	86-90

Appendix 6. Coded transcript	91-100
Appendix 7. Confirmation of ethics approval from Canterbury Christ Church University	101-102
Appendix 8. NHS Health Research Authority Letter of Approval	103-106
Appendix 9. Informed consent questions.....	107
Appendix 10. Consent form.....	108-111
Appendix 11. Interview schedule.....	112-113
Appendix 12. End of study form.....	114-116
Appendix 13. Table illustrating which papers each theme occurred in.....	117

MEGAN MONTGOMERY BSc Hons MSc

MAJOR RESEARCH PROJECT

Section A: Literature Review

A Systematic Literature Review of How People with Learning Disabilities Experience Social Media

Word count: 6447 (+160)

May 2022

Salomons Institute

Canterbury Christ Church University

Abstract

Social Capital Theory (Lin, 2016) proposes that individuals and communities gain resources or 'social capital' through systems of interpersonal relationships. Research has investigated the impact of social media use in terms of social capital and aspects of mental health. Research into social media use by people with learning disabilities is much more limited. The most recent review of the literature in this area was conducted by Caton & Chapman (2016). The current review aimed to provide an updated synthesis of research in this area, answering the question, 'how do people with learning disabilities experience social media?'. A literature search was conducted, 15 studies were included, involving both qualitative and quantitative papers. Quality appraisal tools were used to critique the studies. The findings were grouped into three themes; feelings and attitudes towards social media, opportunities (sub-themes; independence and autonomy, developing and expressing identity, connection and belonging), challenges and support networks. Implications for clinical practice were that clinicians should enquire about people with learning disabilities' (PWLD) social media use as both a potential resource and contributing factor to distress. Recommendations for future research included the creation of a model of social media use, in order to further understand how people with learning disabilities experience social media. Implications for clinical practice and research are discussed.

Introduction

Terminology

Learning disabilities

The label 'learning disabilities' is used to describe a heterogeneous group of people who have 'significant impairment in intellectual functioning and significant impairment in adaptive behaviour (social functioning), with each of these impairments beginning prior to adulthood' (British Psychological Society, 2015, para. 4). There were approximately 1.2 million people living with a learning disability in England in 2019 (Office for National Statistics, 2019). The term 'intellectual disability' is used interchangeably with the term 'learning disabilities' (LD). As 'learning disabilities' is the term most widely used in England at the time of writing (e.g., in NHS and charity sectors), this is the term used throughout this report.

Social media

For the purposes of this study social media is defined as; 'websites and applications that enable users to create and share content or to participate in social networking' (Oxford English Dictionary, 2020). In 2021 it was estimated that 77.9% of the population used social media in the UK (Data Reportal, 2021). The mostly commonly used social media platforms in 2021 were Facebook, YouTube, WhatsApp, Instagram and TikTok (Statista, 2022). This review will refer to 'passive' consumption of social media, which refers to observing content shared by others and 'active' use, which involves the sharing of messages, photos, and life stories online (Burke et al., 2011).

The affordances and constraints of social media use

Online interactions on social media have become a part of daily life for many adults and adolescents alike, as such, social media now contributes to the formation of our social landscape. Research into the experience of social media and the various risks and benefits has increased in recent years. The nature of online interactions is inherently different from those that occur offline,

due to being text based and void of eye contact. The absence of eye contact in interactions has been found to increase self-disclosure, reportedly due to promoting more direct and relaxed exchanges (Mesch & Talmund, 2010). Whilst self-disclosure is reported to promote reduction in emotional distress (Hollenbaugh & Ferris, 2014), the public nature of social media also increases the chances of receiving online hate (Chukwuere & Chukwuere, 2017). This highlights the duality of social media and provides a suggestion as to the opportunities and challenges it brings.

Research in recent years has investigated the impact of social media use on mental health and wellbeing. A recent umbrella review which considered 25 reviews between 2019 – 2021, found most studies presented inconsistent or weak associations between social media use and mental health in adolescence (Valkenburg et al., 2022). The authors highlighted gaps in research such as a need for more clarity regarding definitions of social media use and mental health and data collection methods that do not rely on self-report measures. A study assessing the impact of social media use on measures of social connectedness, fear of missing out and mental wellbeing found no significant relationships between these factors and time spent on social media (Brown & Kuss, 2020). However, after trialling a seven-day abstinence from social media, participants reported a significant decrease in fear of missing out, and an increase in mental well-being and social connectedness. These findings were in line with previous research (Hunt et al., 2018). The participants reported they felt motivated to fill their time with other activities and reflected their main motivations for using social media as being a habit and to pass time. However, a limitation of this study is that the participants may have been more likely to use time away from social media positively as a result of being part of the study.

Individual traits have been found to influence styles of engagement with social media. For example, a recent critical review of the literature found social anxiety to lead to more passive use (O'Day & Heimberg, 2021). Passive use of social media has been associated with negative effects on wellbeing due to increased rumination and social comparison (O'Day & Heimberg, 2021; Verduyn et al., 2017). On the other hand, active social media use was found to promote well-being, supposedly due to increased accrual of social capital and feelings of social connection. Research has investigated

specific types of active online interactions and their impact on measures of mental health and well-being. For example, in a correlational study involving over 400 young adults, a significant relationship was found between 'vaguebooking' and suicidality (Berryman et al., 2018). The term vaguebooking refers to people publicly broadcasting vague messages that elicit feelings of concern from others. This suggests that the argument is not quite as simple as passive vs. active social media use and that it may be helpful to measure specific types of social media engagement.

Social Capital Theory

Social Capital Theory describes the systems of relationships that exist in society, which enable society to function successfully (Lin., 2011). Lin (2011) categorised three types of social capital: bonding, which refers to relationships within homogenous groups, bridging, the relationships formed between relatively homogenous groups and finally, linking social capital, the relationships formed between different hierarchical levels. The theory describes how individuals and communities gain resources via these interpersonal relationships. Research has, therefore, investigated the relationship between social media and social capital. Some findings indicate that accrual of bridging social capital is possible through social media, via individuals receiving messages from others (Burke et al., 2017). Other uses, such as broadcasting messages to a wide audience or passively consuming data shared by others was not associated with the building of social capital (Burke et al., 2017). However, passive consumption was found to foster a sense of connectedness for individuals with perceived lower social skills or experiences of social anxiety, despite not directly developing relationships.

There has been further discussion as to whether online social capital is inherently different from that which is gained offline. Investigating this, de Zuniga et al., (2018) found a distinct difference between offline and online social capital. Social capital gained offline was found to predict how individuals connect with their communities, share values and look out for each other. Contrastingly, social capital gained online lead to variable effects. The type of platform used was found to affect

the value obtained from such connections. However, the two avenues of gaining social capital were found to be related as the extent to which people connected with communities virtually predicted offline engagement overtime.

Rationale for review

Social media has become a part of daily life for many people and it can bring opportunities in terms of building relationships, entertainment and identity development. People with learning disabilities are less likely to be able to access social media and it's potential benefits (Patrick et al., 2020), potentially due to beliefs, attitudes and knowledge of caregivers (Lofrgen-Martenson & Sorbring, 2018). It is therefore important to understand the experiences of people with learning disabilities when using social media, to inform how they can best be supported to access potential benefits. The most recently conducted review of how people with learning disabilities experience social media was conducted by Caton & Chapman (2016). The review highlighted benefits of social media such as identity development, strengthening of relationships and enjoyment. Some identified difficulties included safeguarding concerns, inadequate support and accessibility issues such as communication difficulties. The review proposed that the research into this area for PWLD was methodologically weak and would benefit from the creation of theoretical models (Caton & Chapman, 2016). The current review therefore aims to provide an updated synthesis of recent research in this field.

Methodology

Aims and scope

This review aimed to provide an updated synthesis of recent literature regarding how people with learning disabilities experience social media, following a previous review by Caton & Chapman (2016). The search included empirical papers involving people with learning disabilities and/or their support networks, in order to broaden understanding of their experience. Due to the general paucity

of research in this area, studies of all methodologies were included. Following Caton & Chapman (2016), studies were excluded if less than 75% of participants had learning disabilities, to ensure findings were representative of the target population. The search included studies published from 2014, to avoid repetition and capture studies published after the search conducted by Caton & Chapman (2016). Inclusion criteria are outlined in Table 1.

Table 1

Table of inclusion criteria

Inclusion criteria

Full text available in English

Empirical study

Minimum 75% of participants aged 18 or over

Minimum 75% of participants diagnosed with ID

Research focused on social media

Non-specific population sample *

**Studies were excluded if they focused on a particular diagnosis or group e.g., people with Downs*

Syndrome

Literature search

The search was conducted across four databases, PsychINFO, Web of Science – Core Collections, ASSIA and MEDLINE in November 2021, see Table 2 for a summary of search terms. After duplicates were removed, titles were screened, followed by abstracts and finally full texts, leading to 15 being included in the review. The reference lists of these texts were hand searched and papers citing these

studies were searched using Google Scholar. A flow diagram showing the exclusion of texts at each phase is shown in figure 1.

Table 2

Summary of search terms

Summary of search terms:

learning disabilit* OR intellectual disabilit* OR mental handi* OR learning difficult* OR
mental retard* OR intellectual impair*

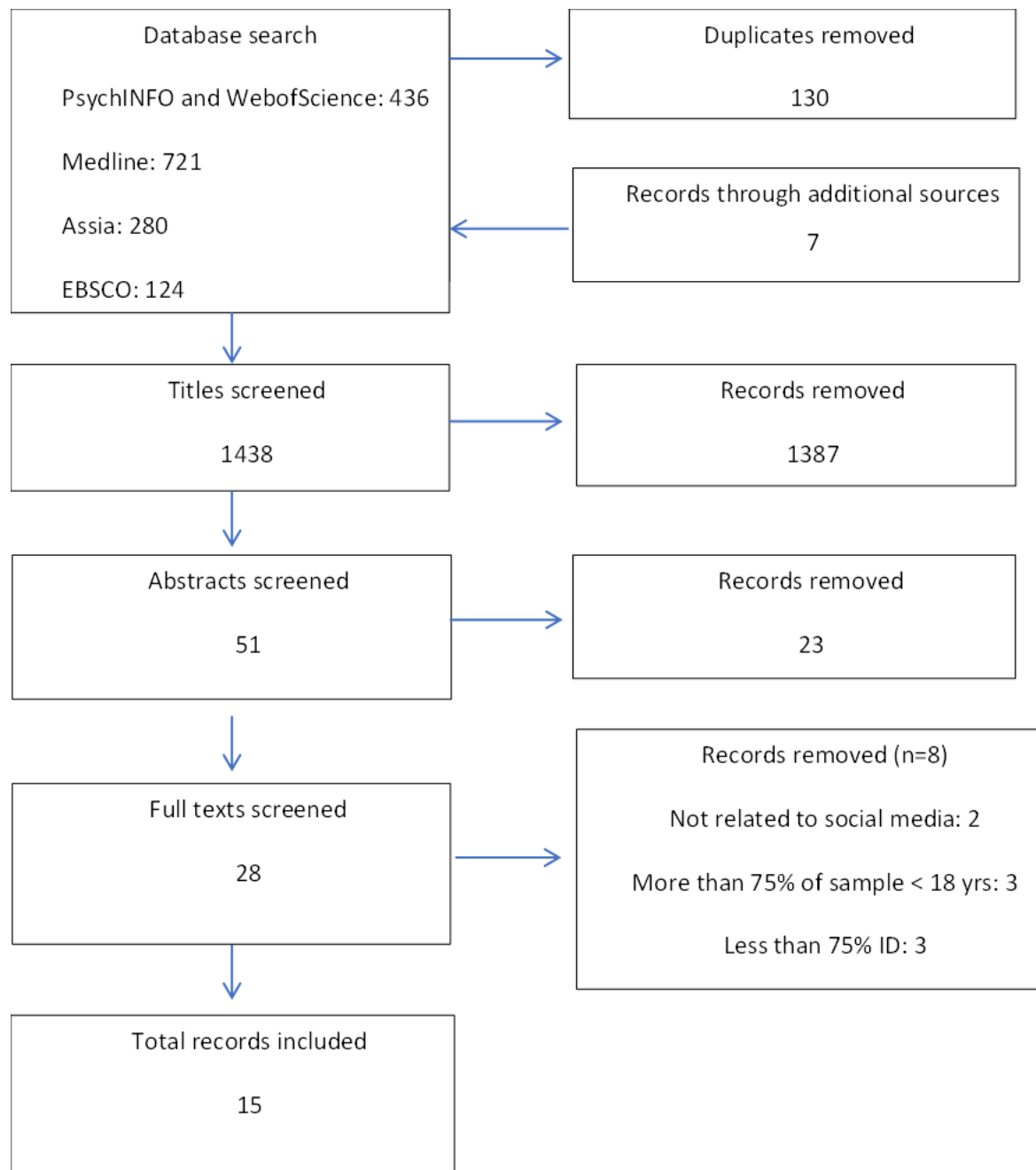
AND

social media OR online social network* OR social networking site OR social network OR
Facebook OR Instagram OR Snapchat OR Twitter OR Bebo OR Myspace OR digital
technolog*

Structure of review

Key characteristics of included studies can be seen in Table 3. The review describes the 15 studies in terms of sample, study design and key findings. The quality of these studies are assessed, the findings are synthesised and discussed in relation to current research. Implications for future research and clinical practice are identified.

Figure 1 Flow diagram demonstrating systematic literature search



Findings

Findings will first be discussed in terms of key study characteristics, a summary of which can be seen in Table 3. This will be followed by a synthesis of key findings, and finally a critique of methodology.

Study characteristics

Eleven studies were qualitative in design, qualitative methodologies included thematic analysis (Chadwick & Fullwood, 2018; Barlott et al., 2020; Shpigelman, 2016; Lines et al., 2020; Bayor et al., 2019), content analysis (Ramsten et al., 2020; Heitplats et al., 2020), post-qualitative analysis (Barlott & Torres, 2021), framework analysis (Williams, 2019), interpretative phenomenological analysis (Darragh et al., 2017) and reporting of case vignettes (Buijs et al., 2016). Two studies were quantitative in design, Kim & Lee (2020) used a correlational design and Davies et al., (2020) used descriptive statistics. Two studies used a mixed methods approach, Chiner et al., (2017) used surveys to collect quantitative and qualitative data, Shpigelman & Gill (2014) used mostly descriptive statistics, the method of qualitative analysis was unclear. The studies varied in focus, although all studies included data regarding social media specifically, seven explored 'information communication technology' or 'the internet' more generally. Many studies took an exploratory approach to how PWLD experience social media, however, some studies took a more focused approach. Darragh et al., (2017) focused on how PWLD use social media for sexual expression, Lines et al., (2020) explored how formal caregivers feel about their role in supporting PWLD with intimate relationships online. Buijs et al., (2016) aimed to portray the 'internet dangers' that PWLD are exposed to on social media and Barlott & Torres (2021) investigated how PWLD developed relationships with technology and whether digital inclusion was indeed beneficial.

Sample characteristics

The majority of papers included PWLD only, two included formal caregivers and PWLD in their sample (Heitplats et al., 2020 and Chiner et al., 2017). One study included family members and formal caregivers alongside PWLD (Bayor et al., 2019), another included formal caregivers only (Lines et al., 2020). Ages of PWLD ranged from 18 - 66 years. No studies recorded ethnicity of participants. Sample sizes ranged from two – 298 for people with learning disabilities and eight – 68 for formal caregivers/ family members.

Three studies were conducted in the United Kingdom (Chadwick & Fullwood, 2018; Williams, 2019; Lines et al., 2020), three in the USA (Davies et al., 2015; Shpigelman & Gill, 2014; Bayor et al., 2019) and three in Australia (Barlott et al., 2020; Barlott & Torre, 2021; Darragh et al., 2017). Three studies were conducted in Europe including Sweden (Ramsten et al., 2020), Germany (Heitplats et al., 2020) and Spain (Chiner et al., 2017). Studies were also conducted in South Korea (Kim & Lee, 2020), Israel (Shpigelman, 2016) and Canada (Buijs et al., 2016).

Four studies did not report inclusion criteria (Buijs et al., 2016; Chadwick & Fullwood, 2018; Heitplats et al., 2020; Williams, 2019). Those that did stated PWLD must be over 18 years of age and have a diagnosis of a learning disability. Lines et al., (2020) who only included formal caregivers stated they must have at least 1 years' experience working with PWLD. Only three studies stated participants must use social media, (Shpigelman & Gill, 2014; Shpigelman, 2016; Ramsten et al., 2020).

Table 3.*Summary of key study information*

Authors/Year	Title	Journal/Country	Study Design	Participants	Key findings
1. Davies et al., (2015)	An Interface to Support Independent Use of Facebook by People with Intellectual Disability	Intellectual and Developmental Disabilities. United States	Participants were trained in using Endeavor Connect, a program designed to support independent Facebook use. Performance on 5 Facebook tasks was measured pre and post training.	12 adults with LD aged 20-45yrs (M=29). 5 females and 7 males.	11 participants completed the Facebook tasks with fewer than 3 prompts or errors when using Endeavor Connect, compared with 4 participants managing this on the mainstream Facebook site.
2. Chadwick & Fullwood (2018)	An online life like any other Identity, self-determination, and social networking among adults with intellectual disabilities	Cyberpsychology, behaviour and social networking. United Kingdom	Semi-structured interviews conducted face to face and on Facebook messenger. Interviews were analysed using semantic and thematic network analysis.	11 adults with LD, 5 female and 6 male aged 20 – 43 (M=29), recruited from self-advocacy groups	Social media was found to facilitate social capital development, relationship maintenance, identity expression and development and a space to develop self-efficacy and self-worth.
3. Barlott et al., (2020)	Connectedness and ICT: Opening the door to possibilities for people with intellectual disabilities	Journal of Intellectual Disabilities. Australia	Community-based participatory research. Semi-structured interviews analysed using thematic analysis	10 adults with LD, 2 female and 8 male aged 21-58 (M=39)	Social support was found to be important in creating opportunities for digital inclusion. Researchers noted possibilities brought by ICT use in terms of connection with others
4. Shpigelman &	How do adults with	Disability & Society.	Online self-report	58 adults with ID,	Participant's experience

Gill (2014)	intellectual disabilities use Facebook?	United States	survey with quantitative and qualitative questions	female (57.9%), 30 years and older (57.9%). Recruited via advertising on disability groups Facebook pages and mailing lists of the disability community	of Facebook was generally positive. Uses included connecting with family and off-line friends. Access issues were found to limit equal participation.
5. Kim & Lee (2020)	Internet use among adults with intellectual and developmental disabilities in South Korea	Journal of Applied Research in Intellectual Disabilities. South Korea	Quantitative study using a survey and structured interview.	298 adults with learning disabilities, 86 female and 122 male aged 18-59 years (M=31)	PWLD use internet for recreation and leisure. Increased age and severity of disability were negatively correlated with internet use. Digital literacy, attitudes and greater material access were related to greater internet use.
6. Shpigelman (2016)	Leveraging social capital of individuals with intellectual disabilities through participation on Facebook	Journal of Applied Research in Intellectual Disabilities. Israel	Qualitative observations of Facebook use and follow up exploratory interviews. Data was analysed using thematic analysis.	20 adults with learning disabilities, 10 male and 10 female, aged 21-43 years (M=30.2)	Use of Facebook was found to enhance bonding, social capital, sense of popularity and belonging.
7. Barlott & Torre (2021)	A socioemotional analysis of technology use by people with intellectual disabilities	Journal of Intellectual Disability Research. Australia	Post-qualitative approach, researchers reanalysed interviews	10 adults with learning disabilities, 2 female and 8 male, aged between 21 and 58 years (M=39.7)	Findings suggested that digital inclusion practises may unintentionally harm people with learning disabilities if it leads to marginalising experiences.
8. Williams	Facebook use by	New Trends and Issues	Qualitative study. All	114 adults with	Facebook was found to

(2019)	people with learning disabilities: The case for facilitated, guided autonomy	Proceedings on Humanities and Social Sciences. United Kingdom	participants attended group Interviews, 72 follow up interviews were conducted. Transcripts were framework analysed	learning disabilities, aged 18-64 years. N=72 qualitative interviews	be a tool for enjoyment, self-expression, and social engagement. However, some PWLD were reluctant to engage for fear of ridicule. Supporters of PWLD noted balance of protecting against harm and facilitating engagement.
9. Ramsten et al., (2020)	Information and communication technology use in daily life among young adults with mild-moderate intellectual disability	Journal of Intellectual Disabilities. Sweden	Qualitative semi-structured interviews. Data was analysed using inductive content analysis	11 adults with learning disabilities, six men and five women, aged 22–31 years	Findings suggested that individuals used ICT for developing and maintain relationships with friends and family, accessing daily support and for engaging in interactions based on interests. Family members were important providers of support for ICT use.
10. Bayor et al., (2019)	Leveraging participation: supporting skills development of young adults with intellectual disability using social media	ASSETS United States	Participatory approach using a series of collaborative technology workshops. Data was collected via observations and videos of the workshops	11 young adults with learning disabilities, six males and five females aged 18-34 years. Participants also included 8 parents and 2 support staff	Findings suggested that improved accessibility of apps and support from family members are both support people with learning disabilities in developing digital skills.
11. Heitplats, Hastall, & Buhler	Usage of digital media by people with	Journal of Intellectual Disabilities.	Semi-structured interviews + focus	24 caregivers and 50 people with LD	Perspectives on digital media usage differ

(2020)	intellectual disabilities: Contrasting individuals' and formal caregivers' perspectives	Germany	groups. Analysed using inductive content analysis investigate attitudes of both formal caregivers and people with intellectual disabilities in Germany regarding their usage of digital media.		between people with intellectual disabilities and formal caregivers regarding (i) interest in accessing the Internet and digital media, (ii) interest in education programs, and (iii) the variety of applications used.
12. Chiner, Gomez-Pureta, & Cardona-Molto, (2017)	Internet use, risks and online behaviour: The view of internet users	British Journal of Learning Disabilities. Spain	A mixed methods, cross-sectional study	77 adults with learning disabilities, 49 male and 28 female, aged 18-51 years (M = 25). 68 carers from Spanish service provider.	Findings indicated increased use of social media use. Exposure to online risks were highlighted, as were undesirable behaviours of group. Differences were found between responses from individuals with LD + their carers
13. Buijs et al., (2016)	Internet Safety Issues for Adolescents and Adults with Intellectual Disabilities	Journal of Applied Research in Intellectual Disabilities. Canada	Reporting of three case vignettes from clinical practice. 2 > 18, 1 under 18.	2 adults with learning disabilities, one male and one female, both in their early twenties	Findings suggest that internet risks are be significant for adolescents and adults with intellectual disabilities. Clinicians should discuss online use, its possible benefits and risks, on a regular basis with this population.
14. Lines et al., (2020)	Exploring how support workers understand their	Journal of Applied Research in Intellectual	Participatory research design, focus group to develop interview	8 support workers (5 females, 3 males) of adults with LD with 1 –	Support workers said that adults with intellectual disabilities should have

	role in supporting adults with intellectual disabilities to access the internet for intimate relationships.	Disabilities. United Kingdom	schedule. Semi-structured interviews, thematic analysis.	15 years experience working with this population.	access to the Internet for intimate relationships. There was a range of views on whether it was their job to support this. A lack of training in Internet use was highlighted.
15. Darragh et al., (2017)	Let's talk about sex: How people with intellectual disability in Australia engage with online social media and intimate relationships.	Cyberpsychology: Journal of Psychosocial Research on Cyberspace. Australia	Interpretative phenomenological approach, semi-structured interviews.	30 adults with an intellectual disability (22 males, 8 females), aged between 20 to 66 years. Purposively sampled through disability organisations	people with intellectual disability exercised cyber safe practices without any explicit formal education and conducted themselves in a respectful manner. Few participants acted in a manner that appeared to put them at risk of exploitation.

Synthesis of findings

The findings relating to social media use have been grouped into three themes; feelings and attitudes towards social media, opportunities (sub-themes; independence and autonomy, developing and expressing identity, connection and belonging), challenges and support networks. Themes were identified by reading the results of each paper and identifying key findings. These findings were then collated across papers to form categories. A category needed to appear in two or more papers in order to be considered a theme. A table illustrating which papers each theme was identified in can be seen in appendix 13. Papers of a higher quality were prioritised and therefore appear more frequently throughout each theme.

Feelings and attitudes towards social media

Studies reported PWLD feeling happy and experiencing positive emotions when using social media (Shpigelman & Gill, 2014; Shpigelman, 2016), these positive feelings were facilitated by enjoyment at looking at photos and videos of others online (Williams, 2019). PWLD reported social media to be an important part of life and reported daily use (Ramsten et al., 2020). However, Barlott & Torres (2021) noted that these positive attributions did not always match with the lived experience of PWLD. For example, participants reported many difficulties and frustration in using social media despite describing it as 'good' and 'brilliant' overall. The authors hypothesise that perhaps social media is perceived positively by PWLD due the status attributed to it by the wider population. Therefore, adopting positive attitudes towards social media provides an opportunity to align with social norms. Barlott & Torres (2021) note the potential implication of societal views on social media research and propose it may have led to the over reporting of benefits for PWLD. The authors warn of the danger of 'inclusion practices' which do not fully consider the potential harm caused by people given access to technologies and applications which do not cater to their individual needs.

Opportunities associated with social media use

Independence and autonomy

PWLD expressed the importance of social media as a platform for self-advocacy (Shpiegleman & Gill, 2014). Social media appeared to be a place where PWLD could act with autonomy in engaging with their goals and interests (Chadwick & Fullwood, 2018). A sense of agency online was facilitated by the gaining of skills in using social media effectively. Chadwick & Fullwood (2018) found six out of eleven participants were able to use social media independently. Independent use of social media was associated with feelings of self-efficacy, self-worth, and self-determination. This process appeared to be enhanced by both the learning of how to use the technology and also the freedom associated with choosing what to access. Participants also offered support to others, furthering a sense of autonomy online and allowing them to adopt the role of a supporter.

Developing and expressing identity

Being on popular social media sites such as Facebook appeared to carry a positive social status for some PWLD, perhaps due to the vast popularity and wide use of the site, this appeared to be a motivation for joining Facebook and facilitated a sense of belonging (Shpigelman, 2016). The authors reported that participants joined Facebook to 'be like everybody else'. This finding was in support of a previous study by Shpigelman & Gill (2014) in which 25% of participants said they 'feel like everyone else' when using Facebook.

PWLD described social media as a place to express identity and "show who I am" (Shpigelman & Gill, 2014). This was achieved through the sharing of life stories and photos and presenting their valued roles online, such as a photo in their work uniform or being with their children (Chadwick & Fullwood, 2018). Individuals discussed developing their identity by connecting with interest groups online (Barlott et al., 2020) and finding inspiration for home décor (Ramsten et al., 2020). Valued roles were also achieved through being a mediator for groups on social media

(Chadwick & Fullwood, 2018). Participants referenced the desire to be visible online (Shpigelman, 2016; Chadwick & Fullwood, 2018) and that this was facilitated by the 'like' function and the sharing of photos. In an observation of PWLD using social media, the importance of being seen was often provided as the reason for interacting with posts (Shpigelman, 2016).

Two studies referenced how PWLD manage their online identity. Chadwick & Fullwood (2018) reported that PWLD were aware of how they presented themselves online and wanted to be perceived as friendly and approachable. The researchers observed individuals making no attempt to hide or mask their learning disability identity and instead observed PWLD focusing on their strengths and valued roles (e.g., parent, friend or spouse). These findings were supported by that of Williams (2019) who also found little evidence for PWLD managing the way they present themselves online. However, Williams (2019) felt individuals did not highlight particular strengths or achievements. This limited focus on impression management lead the researcher to hypothesis that perhaps this is why PWLD may find it hard to understand that people may not be who they say they are online.

Connection and belonging

Many studies referenced PWLD using social media to keep in contact with family and friends from their offline lives via messaging and sharing photos (Barlott et al., 2020; Darragh et al., 2017; Chadwick & Fullwood, 2018; Ramsten et al., 2020; Heitplats et al., 2020). In the study by Shpigelman & Gill (2014) 82% of participants said they felt more comfortable talking to people online rather than face to face. Chadwick & Fullwood (2018) reported that feeling connected with others was the most commonly reported reason for engaging with and enjoying social media. The authors highlighted how this promoted the maintenance of existing social capital. Sense of connection was found to be enhanced by the immediacy of online interactions (Shpigelman, 2016), the voice note function on WhatsApp (Heitplats et al., 2020; Barlott et al., 2020) and the opportunity to communicate using photos and emojis (Barlott et al., 2020), which helped some PWLD overcome written communication difficulties. Participants reported this helping them feel less fearful of stigmatisation, that they

belong and are part of the general population. This feeling of belonging was enhanced by the opportunity for observing non-disabled others (Heitplats et al., 2020). Popularity was also associated with a sense of belonging, Shpigelman (2016) noted that PWLD enjoyed having more contacts on social media as it led to more comments or 'likes' which enhanced a sense of online presence.

Studies differed in the extent to which PWLD appeared to use social media to form new friendships, the majority appeared to only use social media to contact friends and family in their offline lives. Some PWLD highlighted the risks associated with adding unknown contacts when discussing this (Chadwick & Fullwood, 2018). However, some PWLD did report seeking new friendships through shared interest pages online (Ramsten et al., 2020), in the study by Darragh et al., (2017) half of participants reported seeking new romantic relationships on social media. The participants were reported to employ strategies to mitigate risk such as going with a friend/ carer, meeting in a public space and letting someone know where they were going. Interestingly, the researcher commented that participants seemed to be relying on their intuition for these strategies as opposed to having had formal education on the matter. Darragh et al., (2017) was the only study to report the use of social media and digital technology to seek new romantic relationships. PWLD in the study by Chadwick & Fullwood (2018) reported enjoyment of maintaining romantic relationships online but did not mention seeking new romantic relationships online.

Challenges associated with social media

PWLD were reported to experience many challenges in accessing social media due to technical difficulties. Technical difficulties included frequent changes to applications and websites making it difficult to navigate social media sites (Shpigelman & Gill, 2014; Shpigelman, 2016). Challenges also included a lack of resources such as being unable to afford a smartphone or laptop (Williams, 2019; Heitplats et al., 2020). Many studies referenced participants finding it difficult to navigate social media sites in general due to lack of technical skills (Ramsten et al., 2020; Heitplats et al., 2020; Davies et al., 2015). These technical challenges were found to lead to frustration and

limited participation on Facebook (Shpigleman, 2016; Davies et al., 2015; Heitplats et al., 2020). However, PWLD did demonstrate creativity in working around such difficulties, for example using photos instead of words (Heitplats et al., 2020). Chiner et al., (2017); PWLD reported challenges such as being blocked from a group or activity online (48%), receiving hurtful or offensive messages (46%) and unwanted sexual content (35%). There was a discrepancy with reports of carers in the study, who did not think receiving unwanted sexual content online would be a common issue.

Communication abilities were also reported as an issue, participants spoke of avoiding the chat function on Facebook due to the pressure of needing to write quickly (Shpigelman, 2016). Awareness of communication and literacy difficulties led to some PWLD using social media in a more passive way (Williams, 2019), observing content online rather than sharing. The author interpreted this as a sign of a lack of self-confidence. Awareness of being different online, either from communication abilities or body image was apparent in some studies. Some participants spoke of not wanting to share pictures of themselves online for fear of ridicule (Williams, 2019). PWLD's confidence online was also impacted by the attitudes of their support networks, some described feeling afraid to try and access social media because they had been told it was hard (Ramsten et al., 2020). However, despite having an awareness of the difficulties they face online, some PWLD were found to focus more on their abilities when describing their online activity (Chadwick & Fullwood, 2018).

Some challenges also arose from PWLD's understanding and interpretation of online interactions. For example, participants became offended when people did not reply to posts or friendship requests and felt this was the same as being ignored by someone you are talking to (Shpigelman, 2016; Chadwick & Fullwood, 2018). In the case study, Buijs et al., (2017) shared stories of two PWLD in their early twenties who had experienced sexual and financial exploitation as a result of uncritically accepting requests from people they met online. The author described the difficulties these individuals had in understanding the difference between online and offline relationships and the idea that people can pretend to be someone they're not online. In the study by

Heitplats et al., (2020), 29 out of 50 participants said they would like more training or support in accessing social media.

Support networks

Many studies referenced the influence of support networks in social media use. PWLD spoke of being supported with privacy online, understanding 'netiquette' (Chadwick & Fullwood, 2018) and with knowing how much detail to share in posts (Shpigelman, 2016). In one study, lack of social support was raised as a barrier to accessing social media (Ramsten et al., 2020). Accessing social media support was raised as an example of PWLD utilising existing social capital (Chadwick & Fullwood, 2018).

Studies including family members and formal caregivers reported a range of attitudes and beliefs which appeared to influence the support provided to PWLD. In a study including 24 formal caregivers, none reported any positive attitudes towards social media (Heitplats et al., 2020). The caregivers were more likely to describe Facebook as dangerous due to the potential for PWLD to engage in offensive behaviour or get into arguments online. Carers also raised concerns around accessing illegal pornography and signing up to subscription services. Carers highlighted fears regarding who would be responsible for such incidents and the potential costs involved for themselves and the organisation. This appeared to lead to a more risk averse, restrictive approach in supporting PWLD to access social media as all caregivers believed PWLD's social media use should be monitored. The concern that PWLD might engage in undesirable behaviour online was echoed by caregivers in the study by Chiner et al., (2017). Carers expressed concerns that PWLD would engage in inappropriate behaviour online such as insulting others or sending unwanted sexual messages and photos. The frequency of PWLD's actual accounts of engaging in these behaviours were significantly less than the carers assumed. To the contrary, PWLD were more likely to have encountered negative experiences (online bullying, unwanted sexual content) than carers predicted.

In a study of how support workers assist PWLD with intimate relationships online, support workers appeared to discuss their approach in relation to their own moral stance rather than referring to service guidelines (Lines et al., 2020). Although all support workers agreed that access to intimate relationships was a human right, the extent to which they provided support with this varied. The researchers described observing a continuum of support, from actively sending messages or deleting friend requests to a more distanced approach of listening and advising but not ‘pressing that send button’. Fear of blame and feelings of guilt appeared to lead support workers towards more restrictive strategies. Differences were also linked to organisational expectations, as some individuals thought that supporting with relationships was part of their role, and others didn’t. In another study, PWLD commented that they would like to use the internet in order to seek or maintain romantic relationships online, however, were denied access by family members due to safety concerns (Darragh et al., 2017).

The accounts of caregiver’s experiences in supporting PWLD to access social media reflected a tension between a responsibility to promote independence and autonomy and also keep people safe, as was highlighted by Williams (2019), “a complex picture emerged of a delicate interplay between facilitating engagement while protecting against harm”. The author noted that supporters were inclined to lean towards restrictive practices due to fear of the dangers of social media, and PWLD were therefore denied access to the potential benefits. This tension was reflected by PWLD in the study by Barlott et al., (2020) who commented that on the one hand family members were sometimes a barrier in accessing social media due to restrictive practices, however, they were also important in providing teaching of new skills to use devices. This was somewhat dependant on the family members own skills in using social media.

In all studies containing support workers, a need was raised for more training in supporting PWLD to use social media and the internet more generally (Williams, 2019; Lines et al., 2020; Heitplats et al., 2020; Bayor et al., 2019; Chiner et al., 2017). One formal caregiver reflected on the

reluctance of external services to come and provide training for staff on supporting PWLD to access social media and related this to the prejudicial views still held in society (Heitplats et al., 2020).

Quality appraisal

Quality appraisal tools

The eleven qualitative papers included in this review were assessed using the qualitative checklist from the Critical Appraisal Skills Programme (appendix 1, CASP, Singh, 2013). Four papers included in this review were quantitative in design and were assessed accordingly. The study by Davies et al., (2015) was assessed using the Quality Assessment Tool for Before-After (Pre-Post) Studies with No Control Group (NHLBI, 2021, appendix 2). The two survey studies (Kim & Lee, 2020; Shpigelman & Gill, 2014) were assessed using the Quality Assessment Tool for Survey Studies Psychology Checklist (Protogerou & Hagger, 2020, appendix 3). Finally, the cross-sectional survey study by Chiner et al., (2017) was assessed using the Quality Assessment Tool for Cohort and Cross-Sectional Studies (NHLBI, 2021, appendix 4).

Research question and design

All studies clearly stated their aims and the relevance of these aims. Qualitative research appeared to be appropriate for all included papers as they sought to 'highlight the subjective experiences of participants' (CASP, 2018). Papers differed in their design, all but two offered rationales for the chosen methodology (Williams, 2019; Buijs et al., 2020). Three studies stated employing a participatory research design, for example Barlott et al., (2020) utilised a community based participatory research design where providers of literacy programs for PWLD were involved in the process of data analysis. Bayor et al., (2019) also stated they used a participatory approach, although it was not clear what role participants played in the project. Lines et al., (2020) used a participatory research design which involved recruiting a focus group of support workers to develop interview schedules.

Recruitment strategy

All studies other than the case study by Buijs et al., (2016) explained how participants were selected and what inclusion criteria was used. Four studies did not provide a rationale for their recruitment strategy (Chadwick & Fullwood, 2018, Bayor et al., 2019, Chiner et al., 2017; Shpiegleman & Gill, 2014). Purposive sampling was the most widely used recruitment method used by all studies other than Barlott et al., (2020) and Chadwick and Fullwood (2018), who used convenience sampling. The recruitment strategy utilised by Shpiegleman (2016) involved disseminating flyers to community organisations. This may have contributed to the majority of participants having mild learning disabilities as individuals would need to have a certain level of ability in order to respond. A limitation of the study by Darragh et al., (2017) which explored the use of social media for romantic relationships was that only heterosexual people were included in the sample.

Ethical issues

All but three studies recorded having sought approval from an ethics committee (Chadwick & Fullwood, 2018; Williams, 2019; Buijs et al., 2016). The issue of informed consent is important to consider in research involving participants who may find this difficult. Studies varied in the extent to which details were provided regarding how the study was explained to participants. Some papers referenced support workers sharing study information (Barlott et al., 2020; Ramsten et al., 2020; Shpiegleman 2016; Heitplats et al., 2020; Darragh et al., 2017). Chadwick & Fullwood (2018) referenced sending accessible information sheets and consent forms to participants with 'additional checks' to ensure informed consent, however no details were provided regarding what this involved. Many studies did not reference assessing capacity to consent to taking part in the research (Chadwick & Fullwood, 2018; Barlott et al., 2020; Shpiegleman, 2016).

Studies also varied in the extent to which they considered supporting participants to handle the effects of taking part in the study. Chadwick & Fullwood (2018) did state they were present to answer questions during the study and offered a debrief after taking part, however there was no

mention of how participants were supported. Ramsten et al., (2020) demonstrated a process of reviewing consent during the study by observing for signs of distress or tiredness and offering to stop the interview. In the case study paper by Buijs et al., (2016) there was no reference to whether the clients involved had been consulted regarding their involvement in the paper. None of the quantitative studies reported on debriefing participants at the end of the study (Chiner et al., 2017, Davies et al., 2015, Shpigelman & Gill, 2014, Kim & Lee, 2020).

Data collection

The majority of studies clearly explained the data collection process. In the case study paper, (Buijs et al., 2016) no explanation was given regarding why those cases were selected. Studies varied in the extent to which they provided a rationale for the chosen setting and method of data collection. The majority of studies used semi-structured interviews, only one study provided a rationale for this decision, as it was perceived to be the best method for gaining an in-depth exploration of personal experiences (Darragh et al., 2017). Shpigelman (2016) used observations of PWLD using social media in natural settings alongside interviews, with the aim of reducing the influence of the researcher. However, the effectiveness of this is debateable as the researcher is likely to have influenced the behaviour of participants by observing them. Two studies utilised focus groups alongside interviews, Williams (2019) hoped these would provide a non-threatening environment for PWLD due to the groups providing peer-support and validation. Heitplats et al., (2020) used visual supports in their focus groups to ensure people with different communication needs could be included in the discussion, focus groups were chosen due to previous research highlighting the difficulty of gaining perspectives of PWLD using surveys or interview methods. In the quantitative studies, most provided evidence for the validity of measures chosen other than Shpigelman & Gill (2014).

Data collection took place in residential services or specialist community centres in all studies. No studies provided justification for the chosen setting, however, Lines et al., (2020) did highlight potential limitations such as support workers minimising risk or ethical concerns due to

protecting the organisation. One study offered face to face or online interviews (via Facebook messenger) in order to cater for different communication needs (Chadwick & Fullwood, 2018). Participants were offered to have a support worker present in many studies, this may have influenced the information shared by participants. All studies provided an interview guide other than Williams (2019). The CASP checklist asks whether the researcher has discussed saturation of data, only Shpigelman (2016) reported continuation of data collection until saturation had been reached. However, the concept of saturation is contested in qualitative research (Nelson, 2016) and so this may be a limitation of the CASP checklist.

Data analysis, quality assurance and findings

Most studies provided an in-depth description of analysis and provided clear examples of how findings were derived from data. In the community-based participatory study, Barlott et al., (2020) described the stages of analysis well, however, this could have been improved by providing examples of how the organisation leaders contributed to the formation of categories. Williams (2019) stated framework analysis was used to interpret the data, however, no further detail was provided as to how this occurred. A further limitation of the study by Williams (2019) was that insufficient examples from the data were provided to substantiate findings. This was also the case for Bayor et al., (2019). Few studies discussed the credibility of their findings, Shpigelman (2016) commented enhancing credibility via triangulation of data from observations and interviews and the analysis process being reviewed by a peer. Shpigelman (2016) also mentioned keeping a reflective journal and referencing this during the process of analysis. Lines et al., (2020) described accessing support from a qualitative research group at a university for revision of the categories and made adjustments accordingly. In terms of reflexivity, Lines et al., (2020) reflected on their 'professionally privileged' background and how this may have led them to place more emphasis on training needs and supervision in their questioning. Ramsten (2020), Chadwick & Fullwood (2018) and Barlott & Torres (2021) both had more than one researcher analyse the data to enhance credibility. Barlott et

al., (2020) and Barlott & Torres (2021) also included community partners in the revision of categories, however, there was no mention of researcher bias and how this influenced the final results. In the interpretative phenomenological analysis study by Darragh et al., (2020) there was no mention of researcher reflexivity which is a particular limitation given this being considered an important tenant of this method. Finally, Williams (2019) provided no discussion of researcher bias or the quality of findings in general.

Most studies did discuss the implications of findings in relation to existing knowledge and future research. For example, Ramsten et al., (2020) discussed the need for further research to understand the contextual aspects of how PWLD access and experience social media, such as the impact of societal views. One study (Williams, 2019) did not provide any discussion of the implications of findings.

Discussion

The aim of this review was to provide an updated answer to the question ‘what do we know about how people with learning disabilities experience social media?’, following the review by Caton & Chapman (2016). The current review found that social media maintains to be an important part of life for PWLD, providing opportunities for connection, identity expression and independence. Overall, the research appeared to present a positive view of social media. Perhaps this is a reflection of the positive status that society as a whole as attributed to social media (Barlott & Torres, 2021). This could also be the result of researchers wanting to promote digital inclusion practices, thereby focusing more on the possible benefits. This apparent focus on more positive representations of social media may limit the robustness of any conclusions drawn from this study. Validity of conclusions is further limited by the variation in the quality of included studies. In terms of Social Capital Theory (Lin, 2011), Chadwick & Fullwood (2018) noted the possibility of maintaining existing social capital through accessing social media.

Research implications

The papers in this review only included PWLD who accessed social media, perhaps future research could include those who do not access social media, in order to explore what factors are leading to this. The possibility of PWLD gaining social capital from social media may be an area for future research to consider, based on the finding that it can be helpful for people with lower social fluency (Chadwick & Fullwood, 2018). More focused research into the types of activities PWLD engage in online and how severity of LD, communication abilities and social confidence influence this may be helpful. Finally, it may be helpful for future research to build a model in order to explain how PWLD experience social media in order to understand how different factors relate to each other.

Clinical implications

PWLD were found to have positive experiences online including feeling connected with others (Barlott et al., 2020; Darragh et al., 2017; Chadwick & Fullwood, 2018) and being able to develop and express their identity (Ramsten et al., 2020; Barlott et al., 2020; Chadwick & Fullwood, 2018). It may therefore be important for clinicians to ask PWLD about their experience of social media as a potential resource for alleviating loneliness and developing a sense of self. Social media was also found to present challenges including accessibility issues, risk of exploitation and the potential for online hate. However, PWLD did demonstrate awareness of these risks and some skills in mitigating them (Heitplats et al., 2020). Clinical psychologists may play a role in the provision of training for staff members supporting PWLD to navigate these difficulties. These challenges may also exacerbate or maintain mental health issues and therefore could be important to investigate during assessment for such difficulties.

This review also found that supporters of PWLD (e.g. support workers, family members) may hold negative views about social media which may lead to restrictive practices (Williams, 2019; Lines et al., 2020; Heitplats et al., 2020; Bayor et al., 2019; Chiner et al., 2017). Clinical psychologists could

play a role in providing training to inform individuals about the benefits of social media alongside the risks, and how best to support PWLD to access it. The provision of this training may assist supporters of PWLD in building a clearer understanding of best practice in supporting PWLD to use social media rather than relying on their 'own moral code' (Lines et al., 2020). This could help promote consistency of approach across LD services and ultimately facilitate PWLD in accessing the many potential benefits of social media use as identified in this review.

Conclusion

Overall, the included studies varied in their credibility and demonstrated various benefits and challenges of accessing social media. The findings of this study are similar to that of Caton & Chapman (2016). Future research would benefit from building a model of how people with learning disabilities access social media in order to understand how different factors relate to each other. Clinical implications include the need for training for people who support PWLD and greater awareness of PWLD social media use in assessments and therapeutic interventions.

References

- Barlott, T., & Torres, M., (2020). A socio-emotional analysis of technology use by people with intellectual disabilities. *Journal of Intellectual Disability Research*, 65(2), 149–161. <https://doi.org/10.1111/jir.12796>
- Barlott, T., Aplin, T., Catchpole, E., Kranz, R., Le Goullon, D., Toivanen, A., & Hutchens, S. (2020). Connectedness and ICT: Opening the door to possibilities for people with intellectual disabilities. *Journal of Intellectual Disabilities*, 24(4), 503–521. <https://doi.org/10.1177/1744629519831566>
- Bayor, A. A., Sitbon, L., Ploderer, B., Bircanin, F., Koplick, S., & Brereton, M. (2019). Leveraging participation. *The 21st International ACM SIGACCESS Conference on Computers and Accessibility*. <https://doi.org/10.1145/3308561.3353793>
- Berryman, C., Ferguson, C. J., & Negy, C. (2018). Social media use and mental health among young adults. *Psychiatric Quarterly*, 89(2), 307–314. <https://doi.org/10.1007/s11126-017-9535-6>
- Brown, L., & Kuss, D. J. (2020). Fear of missing out, mental wellbeing, and social connectedness: A seven-day social media abstinence trial. *International Journal of Environmental Research and Public Health*, 17(12), 4566. <https://doi.org/10.3390/ijerph17124566>
- Buijs, P. C., Boot, E., Shugar, A., Fung, W. L., & Bassett, A. S. (2016). Internet safety issues for adolescents and adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 30(2), 416–418. <https://doi.org/10.1111/jar.12250>
- Burke, M., Kraut, R., & Marlow, C. (2011). Social Capital on Facebook: Differentiating users and uses . *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. <https://doi.org/10.1145/1978942.1979023>
- Caton, S., & Chapman, M. (2016). The use of social media and people with intellectual disability: A systematic review and thematic analysis. *Journal of Intellectual and*

- Developmental Disability*, 41(2), 125–139.
<https://doi.org/10.3109/13668250.2016.1153052>
- Chadwick, D. D., & Fullwood, C. (2018). An online life like any other: Identity, self-determination, and social networking among adults with intellectual disabilities. *Cyberpsychology, Behavior, and Social Networking*, 21(1), 56–64.
<https://doi.org/10.1089/cyber.2016.0689>
- Chiner, E., Gómez-Puerta, M., & Cardona-Moltó, M. C. (2017). Internet use, risks and online behaviour: The view of internet users with intellectual disabilities and their caregivers. *British Journal of Learning Disabilities*, 45(3), 190–197.
<https://doi.org/10.1111/bld.12192>
- Chukwuere, J. E., & Chukwuere, P. C. (2017). The impact of social media on social lifestyle: a case study of university female students. *Gender and Behaviour*, 15(4), 9966-9981.
<https://hdl.handle.net/10520/EJC-c1e3ae5f6>
- Darragh, J., Reynolds, L., Ellison, C., & Bellon, M. (2017). Let's talk about sex: How people with intellectual disability in Australia engage with online social media and intimate relationships. *Cyberpsychology: Journal of Psychosocial Research on Cyberspace*, 11(1).
<https://doi.org/10.5817/cp2017-1-9>
- Davies, D. K., Stock, S. E., King, L. R., Brown, R. B., Wehmeyer, M. L., & Shogren, K. A. (2015). An interface to support independent use of Facebook by people with intellectual disability. *Intellectual and Developmental Disabilities*, 53(1), 30–41.
<https://doi.org/10.1352/1934-9556-53.1.30>
- de Zúñiga, H. G., Barnidge, M., & Scherman, A. (2018). Social media social capital, offline social capital, and citizenship: Exploring asymmetrical social capital effects. *Digital Politics: Mobilization, Engagement and Participation*, 44–68.
<https://doi.org/10.4324/9780429459955-4>
- Heitplatz, V. N., Bühler, C., & Hastall, M. R. (2021). Usage of digital media by people with intellectual disabilities: Contrasting individuals' and formal caregivers' perspectives.

Journal of Intellectual Disabilities, 174462952097137.

<https://doi.org/10.1177/1744629520971375>

Hollenbaugh, E. E., & Ferris, A. L. (2014). *Facebook self-disclosure: Examining the role of traits, social cohesion, and motives*. *Computers in Human Behavior*, 30, 50–58.

Hunt, M. G., Marx, R., Lipson, C., & Young, J. (2018). No more Fomo: Limiting social media decreases loneliness and depression. *Journal of Social and Clinical Psychology*, 37(10), 751–768. <https://doi.org/10.1521/jscp.2018.37.10.751>

Joyce, T., Bankhead, I., King, S., Liddiard, H., & Willner, P. (2015). *Guidance on the assessment and diagnosis of intellectual disabilities*. The British Psychological Society. Retrieved May 5, 2022, from <https://www.bps.org.uk/sites/www.bps.org.uk/files/Member%20Networks/Faculties/Intellectual%20Disabilities/Guidance%20on%20the%20Assessment%20and%20Diagnosis%20of%20Intellectual%20Disabilities%20in%20Adulthood.pdf>

Kemp, S. (2021, November 4). *Digital in the United Kingdom: All the statistics you need in 2021 - DataReportal – global digital insights*. DataReportal. Retrieved May 5, 2022, from <https://datareportal.com/reports/digital-2021-united-kingdom#:~:text=There%20were%2065.32%20million%20internet,at%2096.0%25%20in%20January%202021.>

Kim, K. M., & Lee, C. E. (2020). Internet use among adults with intellectual and developmental disabilities in South Korea. *Journal of Applied Research in Intellectual Disabilities*, 34(3), 724–732. <https://doi.org/10.1111/jar.12843>

Lin, N. (2011). *Social Capital: A theory of social structure and action*. Cambridge University Press.

Lines, J., Combes, H., & Richards, R. (2020). Exploring how support workers understand their role in supporting adults with intellectual disabilities to access the internet for intimate relationships. *Journal of Applied Research in Intellectual Disabilities*, 34(2), 556–566. <https://doi.org/10.1111/jar.12822>

Löfgren-Mårtenson, L., Molin, M., & Sorbring, E. (2018). H@ssles and hopes on the internet: What professionals have encountered in dealing with internet use and sexuality among youths with intellectual disabilities. *Papers of Social Pedagogy*, 8(1), 66–82. <https://doi.org/10.5604/01.3001.0011.5851>

Löfgren-Mårtenson, L., Molin, M., & Sorbring, E. (2018). H@ssles and hopes on the internet: What professionals have encountered in dealing with internet use and sexuality among youths with intellectual disabilities. *Papers of Social Pedagogy*, 8(1), 66–82. <https://doi.org/10.5604/01.3001.0011.5851>

Mesch, G., & Talmud, I. (2010). *Wired Youth: The Social World of Adolescence in the Information Age* (1st ed.). Routledge. <https://doi.org/10.4324/9780203855102>

Nelson, J. (2016). Using conceptual depth criteria: Addressing the challenge of reaching saturation in qualitative research. *Qualitative Research*, 17(5), 554–570. <https://doi.org/10.1177/1468794116679873>

O’Day, E. B., & Heimberg, R. G. (2021). Social media use, social anxiety, and loneliness: A systematic review. *Computers in Human Behavior Reports*, 3, 100070. <https://doi.org/10.1016/j.chbr.2021.100070>

Oxford English Dictionary. (2020). Social media. <https://www.oed.com/view/Entry/183739?redirectedFrom=social+media#eid272386371>

Patrick, P. A., Obermeyer, I., Xenakis, J., Crocitto, D., & O’Hara, D. M. (2020). Technology and social media use by adult patients with intellectual and/or developmental disabilities. *Disability and Health Journal*, 13(1), 100840. <https://doi.org/10.1016/j.dhjo.2019.100840>

Protogerou, C., & Hagger, M. S. (2020). A checklist to assess the quality of survey studies in psychology. <https://doi.org/10.31234/osf.io/uqak8>

Ramsten, C., Martin, L., Dag, M., & Hammar, L. M. (2018). Information and communication technology use in daily life among young adults with mild-to-moderate intellectual disability. *Journal of Intellectual Disabilities, 24*(3), 289–308.
<https://doi.org/10.1177/1744629518784351>

Shpigelman, C. N., & Gill, C. J. (2014). How do adults with intellectual disabilities use Facebook? *Disability & Society, 29*(10), 1601–1616.
<https://doi.org/10.1080/09687599.2014.966186>

Shpigelman, C.-N. (2016). Leveraging social capital of individuals with intellectual disabilities through participation on Facebook. *Journal of Applied Research in Intellectual Disabilities, 31*(1). <https://doi.org/10.1111/jar.12321>

Singh, J. (2013). Critical appraisal skills programme. *Journal of Pharmacology and pharmacotherapeutics, 4*(1), 76. doi:10.4103/0976-500X.107697

Sparkes, I. (2019, December 2). *Disability and education, UK: 2019*. Disability and education, UK - Office for National Statistics. Retrieved May 5, 2022, from <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/bulletins/disabilityandeducationuk/2019>

Statista Research Department. (2022, March 8). *Most used social media 2021*. Statista. Retrieved May 5, 2022, from <https://www.statista.com/statistics/272014/global-social-networks-ranked-by-number-of-users/#:~:text=In%202022%2C%20Social%20networking%20sites,traction%20in%20previously%20underserved%20markets.>

Study Quality Assessment Tools | NHLBI, NIH. Nhlbi.nih.gov. (2021). Retrieved 19 June 2021, from <https://www.nlm.nih.gov/health-topics/study-quality-assessment-tools>.

Study Quality Assessment Tools | NHLBI, NIH. Nhlbi.nih.gov. (2021). Retrieved 19 June 2021, from <https://www.nlm.nih.gov/health-topics/study-quality-assessment-tools>.

- Valkenburg, P. M., Meier, A., & Beyens, I. (2022). Social media use and its impact on Adolescent Mental Health: an umbrella review of the evidence. *Current Opinion in Psychology, 44*, 58–68. <https://doi.org/10.31234/osf.io/y8zdg>
- Verduyn, P., Ybarra, O., Résibois, M., Jonides, J., & Kross, E. (2017). Do social network sites enhance or undermine subjective well-being? A critical review. *Social Issues and Policy Review, 11*(1), 274–302. <https://doi.org/10.1111/sipr.12033>
- Williams, P. (2019). Facebook use by people with learning disabilities: The case for facilitated, guided autonomy. *New Trends and Issues Proceedings on Humanities and Social Sciences, 6*(5), 99–108. <https://doi.org/10.18844/prosoc.v6i5.4379>

Megan Montgomery BSc Hons MSc

MAJOR RESEARCH PROJECT

Section B: Empirical Paper

A Grounded Theory of How People with Learning Disabilities Experience Social Media

Word count: 7836 (+227)

May 2022

Salomon's Institute

Canterbury Christ Church University

To protect anonymity all identifying information has been removed

Abstract

The stigmatization of people with learning disabilities continues to affect their lives today. Use of social media has become a part of daily life for many people, however, research has shown that people with learning disabilities have more difficulties accessing social media and may be more vulnerable to negative experiences online. Current research is yet to develop a model of how people with learning disabilities experience social media. Grounded theory was used to analyse interviews with people with learning disabilities who use social media. The data consisted of interviews with 10 people with learning disabilities (PWLD) and one support worker from a national learning disabilities (LD) charity. A preliminary theoretical model was developed, suggesting that people with learning disabilities face many opportunities and challenges when navigating the online world and that doing so leads to a sense of being seen online. This visibility poses opportunities for feelings of connection and belonging alongside increased exposure to disability stigma. Participants demonstrated a range of skills and attitudes in facing this stigma.

Introduction

Stigmatization of people with learning disabilities

The lives of people with learning disabilities (PWLD) have been governed by shifting societal beliefs throughout history. The eugenics movement in the 19th and 20th centuries lead to the segregation and institutionalisation of PWLD who were thought to be a threat to the national gene pool (Barker, 1983). A later contrasting belief was that PWLD were 'eternal children' and therefore asexual, as children were once believed to be (Franco et al., 2012). This historical context and stigma surrounding this population continues to affect their lives today. This is evident in a range of inequalities, adults with learning disabilities are significantly less likely to be in paid employment (NHS digital, 2022), are more likely to experience abuse and bullying (Chatzitheochari et al., 2014) and have limited opportunities to form relationships (Brown & McCann, 2018; National Development Team for Inclusion, 2019).

Disability stigma has been widely reported to affect the lives of PWLD (Jahoda et al., 2010), impacting on their sense of self-worth and identity (Logeswaran et al., 2020). Internalisation of discriminatory views can lead to self-stigma, a process whereby people view this aspect of themselves as socially unacceptable (Vogel et al. 2007). The stepwise model of self-stigma by Corrigan & Rao (2012) suggests that self-stigmatisation begins with awareness of a negative stereotype, followed by uncritical acceptance of the label. This leads to detrimental outcomes for the individual, such as a reduction in confidence and self-belief, which can affect motivation to set and work towards goals (Corrigan et al., 2009). A review of the literature found support for the relevance of this model within the learning disability population (Sheehan & Ali, 2017). Few studies have explored the relationship

between self-stigma and self-esteem amongst PWLD, however, higher rates of stigmatizing experiences have been found to be linked to lower self-esteem (Szivos-Bach, 2010; Paterson et al., 2012). Research has found a positive correlation between rates of discriminatory experiences and prevalence of anxiety and depression, particularly in lower-economic populations and those with less social support (Emerson, 2010; Paterson et al., 2012; Ali et al., 2015).

Social media and PWLD

Social media use is prevalent within the learning disabilities population, a survey of 216 young adults with learning disabilities found internet and phone use to be significantly higher than that of their peers (Jenaro et al., 2017). Uses and gratifications theory (Katz & Blumler, 1974) suggests that people use media content in different ways in order to meet particular needs. Prevalent uses and gratifications of social media in the general population include keeping in touch with friends and family, sharing photos and opinions, information seeking and entertainment (Whiting and Williams, 2013; Ezumah, 2018; Gray, 2018). Acts of self-disclosure on social media (e.g., sharing of photos, life stories and opinions) have been found to elicit feelings of connectedness and social support, leading to improvements in wellbeing (Luo and Hancock, 2020). PWLD have reported many benefits from engaging with social media including the development of friendships, social identity and self-esteem (Caton & Chapman, 2016). Social media has been described as a space where adults with learning disabilities can 'be like everybody else' (Löfgren-Martenson, 2008) and somewhere they can explore and express their sexuality (Darragh et al., 2017). The use of social media platforms has been found to reduce feelings of isolation and loneliness within this population (Kydland et al., 2012).

However, PWLD face many barriers in accessing these potential gains from social media use. Glencross et al (2021) argue there is a 'digital divide', PWLD experience digital inequality through lack of access to internet, apps and websites. Accessibility may be governed by usability of apps and restrictions enforced by others (Glencross et al., 2021). This argument is supported by findings that cognitive and language difficulties prevent some individuals from using social media (Caton & Chapman, 2016). Individuals may not receive the required support to access social media, due to limited training opportunities for families and professionals (Chiner et al., 2017). PWLD may be perceived as being more at risk by care providers, leading to risk-averse and restrictive practices. Chalghoumi et al (2019) explored why PWLD may be more at risk online and found limited awareness of security issues in relation to using social media, safety was ensured by supporting caregivers. Increased prevalence of loneliness within this population may contribute to increased risk, alongside reduced ability to assess authenticity of online interactions (Chadwick & Fullwood, 2019).

Social media and identity development

Identity affects an individual's perception and understanding of themselves, their preferences and behaviour (Oyserman et al., 2012). Social media has been found to simultaneously promote autonomy in identity expression and a reliance on validation from others to support one's sense of self-worth (Manago, 2015). Identity process theory (Breakwell & Jaspal, 2014) proposed that identities are formed by a process of incorporating new information into an identity structure and adjusting or evaluating other identity components accordingly. Individuals use coping mechanisms to manage threats to these identities, such as distancing themselves from undesirable aspects. A literature review of

how PWLD construct their social identity found individuals described themselves according to their skills and personal qualities and disability identity was not central to their self-image (Logeswaran et al., 2020). The review found that some people rejected the learning disability label altogether, possibly as a coping mechanism against self-stigma, which may support the identity process theory. Social media can facilitate the process of choosing which aspects of our identities we present to the world, as individuals have much more control over how they present themselves online compared to in their offline lives (Hogan, 2010).

Social media provides vast opportunities for finding and connecting with people that share similar views and therefore validate one's sense of identity. Identity driven use of social media can lead to 'identity bubbles' or 'echo chambers' where people are rarely exposed to beliefs contrasting to their own, which can foster harmful behaviour towards others (Keipi et al., 2017). A study involving 269 adults with learning disabilities found 15% had been bullied online, predominantly via verbal aggressions (Jenaro et al., 2018). The authors found the most common reason for receiving these verbal attacks was 'being different'. The potential benefits to be gained through social media alongside the risks it poses leads to a dilemma of supporting individuals' privacy and autonomy online whilst also ensuring their safety (Wasserman, 2019).

Rationale and aims of this study

Research into social media and PWLD has increased in recent years. However, there are currently no theories or models of social media use within this population. The current study aims to build a model grounded in the experiences of PWLD. It is hoped this model

will help inform our current understanding of how this group experiences and makes use of social media.

Method

Design

This study employed a qualitative grounded theory design (Glaser & Strauss, 1967) which allows the integration of data from a range of sources, from which a model can be built. The researcher took a critical realist perspective whereby research is viewed as a social activity and knowledge is formed about phenomenon which exist independently of the researcher (Bhaskar, 2008). The design of the study was influenced by Urquhart's (2013) description of grounded theory which is accommodating of a critical realist approach.

Recruitment

Participants were initially recruited using purposive sampling from a national learning disabilities (LD) charity (n=6) and an NHS community learning disabilities team (CLDT, n=2). An accessible information sheet (appendix 5) was shared with potential participants by staff, who were advised to contact me directly via phone or email. Theoretical sampling (Urquhart, 2013) was used to build on the emerging model. Theoretical sampling led to a support worker from the national LD charity being invited to take part, as several participants mentioned her being a part of their social media experience during interviews.

Table 1*Eligibility criteria*

Inclusion	Exclusion
Diagnosis of a learning disability and in receipt of or known to a specialist learning disability service (national LD charity or CLDT)	Risk of aggressive behaviour or likelihood of finding interview distressing
Must use some form of social media sites (websites and applications that enable users to create and share content or to participate in social networking)	Unable to provide informed consent
Able to communicate in sentences and discuss abstract topics (e.g. relationships)	
Over the age of 18	

Participants

Eleven participants took part in this study. Ten PWLD were interviewed, aged 30-57 (M=36), three were male and seven were female (Table 2). All participants used social media multiple times a day. Identified social media platforms included Facebook, Instagram, Snapchat, WhatsApp, TikTok, Twitter, YouTube, Telegram and Chatter. One female support worker from the national LD charity also took part.

Data collection

Data was collected using semi-structured interviews which allow the researcher to adapt questions in response to the communication needs of the participant. An interview question guide can be seen in appendix 11. This flexibility promoted the building of rapport and facilitated the exploration of new areas related to the core topic (Magaldi and Berler, 2020). The cooperative nature of this method enabled the researcher attend to any ethical issues as they arose (Gubriam et al., 2012).

Participants were offered face to face (n= 2) or virtual meetings via Zoom (n=6).

Participants from the national LD charity opted for Claire (pseudonym, support worker) to be present during interviews. Face-to-face meetings were held at the CLDT site. Length of interviews varied from 34 – 60 minutes. All interviews were audio recorded and transcribed.

Theoretical sampling led to three follow up interviews to test hypotheses that emerged from the data. Claire (support worker, national LD charity) was invited to be interviewed.

Three participants were asked for consent to contact their family members, all declined.

Table 2

Participant characteristics

Pseudonym	Age	Gender	Ethnicity	Occupation	NHS or national LD charity	Interview location	Types of social media used
Nigel	35	Female	White British	Unemployed	NHS CLDT service	Face to Face	Facebook, Instagram, TikTok and WhatsApp
Hazel	25	Female	White British	Volunteer charity shop, carer	NHS CLDT service	Face to Face	Facebook and WhatsApp
Anne	54	Female	White British	Unemployed	National LD charity	Zoom	Facebook, Instagram and TikTok
Goldy girl	32	Female	White British	Admin worker	National LD charity	Zoom	Facebook, Instagram, YouTube, TikTok and Telegram
Lorraine	37	Female	White British	Cleaner and Admin worker at the national LD charity	National LD charity	Zoom	Facebook, Instagram, and Twitter
Adam	34	Male	White	Membership	National	Zoom	Chatter,

			British	engagement officer at the national LD charity	LD charity		WhatsApp, Twitter and Instagram
Frank	57	Male	White British	Cleaner	National LD charity	Zoom	Facebook, Instagram, Twitter, TikTok, Snapchat
Sam	43	Female	White British	Salvation Army Officer	National LD charity	Zoom	Facebook and WhatsApp
Kayleigh	30	Female	White British	College	NHS CLDT Service	Zoom	Facebook, Instagram and YouTube
David	32	Male	British Turkish	Unemployed	National LD charity	Zoom	Facebook and WhatsApp

Data analysis

A grounded theory approach was used to analyse the data (Glaser & Strauss, 1967). Data collection and analysis took place simultaneously, resulting themes and hypotheses were used to guide theoretical sampling, in line with guidance by Urquhart (2013). A component of grounded theory methodology is to gather data until one has reached 'saturation', whereby no new insights emerge (Glaser and Strauss, 1967). Dey (1999) proposed 'theoretical sufficiency' as a more appropriate term, as the researcher should aim for appropriate conceptual depth to facilitate the building of a theory. Therefore, interviews were conducted until theoretical sufficiency was achieved.

Audio recordings of interviews were transcribed verbatim. Transcripts were analysed using open coding, each line was coded with a combination of descriptive and analytical codes (appendix 6). Following this, open codes were arranged into categories, leading to the

creation of selective codes. A process of constant comparison of transcripts and codes lead to the construction of theoretical codes. These were integrated into a model (Figure 1), which aimed to explain the relationship between them. Theoretical memos and diagrams facilitated this process.

Quality assurance and reflexivity

Reflexivity is considered an important tenant of qualitative research (Yardley, 2016). A bracketing interview (Tufford and Newman, 2010) was carried out with a peer to consider the influence of my own context on the project. My position as an able-bodied, White British, trainee clinical psychologist has shaped my own experiences of social media and may therefore have led to certain biases. I identified my assumptions that PWLD may have more negative experiences on social media and may find it hard to access benefits that others enjoy. As Yardley (2016) states, sensitivity to context is crucial in building quality research due to the influence of the researcher, “the listener contributes to what is said... by actively or passively invoking the relative identities and shared understandings which provide the framework for speech”. Salient differences between myself and participant group may have influenced which aspects of experience they chose to share with me. I took care to maintain a curious and empathetic approach in interviews and follow up interviews were used to explore more sensitive topics once a relationship had been built.

Having previously worked with PWLD as an assistant psychologist, I have experienced supporters of PWLD as being understandably protective and have witnessed how this can lead to restrictive practices. I was aware this could have led me to assume people supporting PWLD hold negative views about social media and so took care to ask open questions. I have no personal experience with some social media platforms, which could

have led to blind spots in my questioning. In the initial interviews I observed myself directing more questions towards Facebook and took care in later interviews to ask about other platforms mentioned by the participants.

Inter-rater reliability has been argued as being impossible in qualitative research due to the subjectivity of interpreting data (Seidel and Kelle, 1995). However, meetings with my supervisor were used to facilitate the analysis of data as we discussed and refined codes, categories, and diagrams of the emerging model.

Ethical considerations

Ethical approval was gained from the university ethics panel (appendix 7), NHS Research Ethics Committee and the Health Research Authority (appendix 8).

Informed consent

Capacity to provide informed consent to participate in the study was assessed on the day of the interview by the researcher, in line with the Mental Capacity Act (2005).

Questions were asked to assess that each participant fully understood the nature of taking part (appendix 9). Participants were to be excluded from the study if they were not able to answer these questions with support. All participants demonstrated informed consent.

Participants were given accessible consent forms and information sheets before the interview by staff members of the National LD charity or the CLDT (appendix 10).

Participants were reminded of their right to withdraw from the study or decline to answer questions and that this would not affect the care they receive. Consent was reviewed throughout the interviews, for example, if participants became visibly tired.

Acquiescence

PWLD are more likely to acquiesce (passively comply) in research due to the researcher's perceived authority (Williams, 2021). Open questions were used as much as possible to limit the influence of the researcher. However, closed questions were used at times to scaffold the questions and support understanding. Although these questions could be considered as leading, it was agreed with my supervisor that this was necessary to facilitate the conversation.

Confidentiality and anonymity

All identifiable information was removed from transcripts, transcripts and audio recordings were encrypted and stored on a password-protected laptop. After transcription, audio files were deleted. Participants were advised that what they say in interviews may be used in the write up of the study. Participants chose pseudonyms to help protect their identity.

Service-user consultation

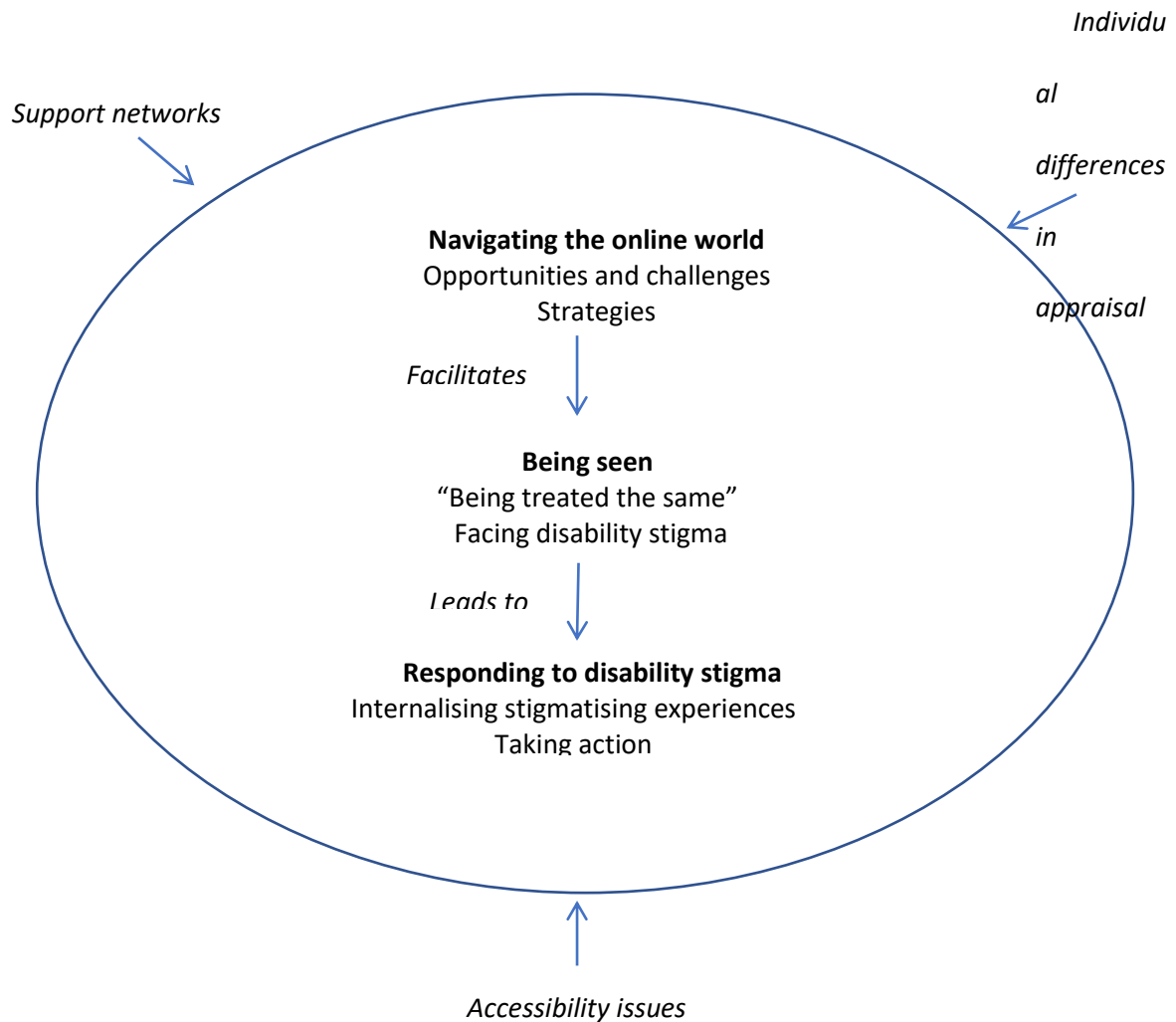
A consultation was held with an NHS volunteer group co-produced by clinicians and PWLD. The group offered recommendations for amendments to be made to the information sheet and consent form to ensure accessibility.

Results

Three categories emerged which formed an initial model of how PWLD experience social media. The categories were navigating the online world, being seen and responding to disability stigma (Figure 1).

Figure 1

Model of how people with learning disabilities experience social media



Overview of model

This preliminary grounded theory model relates to adults with learning disabilities who are accessing specialist support services and use social media. The model presents the challenges and opportunities that arise from social media use and the processes by which PWLD navigate these experiences. Findings led to the construction of three core categories; navigating the online world, being seen online, and responding to disability stigma. Three

mediating factors appeared to influence experiences in each of these categories; support networks, accessibility issues and appraisal of online content.

The model suggests that engagement on social media increases exposure to opportunities and challenges. Some reported opportunities included observing others, engaging with interests, and maintaining relationships. Challenges included risk of being exploited, feeling confused by fake news and fake accounts, and feeling misunderstood. Participants demonstrated a range of strategies to manage these challenges including seeking support, avoiding risk and assessing online content for credibility. Access to these opportunities and ability to navigate challenges was mediated by differences in views of support networks, accessibility issues and differences in how individuals interpreted online content.

This process of navigating the online world appeared to enable a sense of being seen online. Being seen was facilitated by individuals expressing their identities through sharing photos, life events and engaging with community/ interest pages. A sense of visibility online was also facilitated by individuals responding to content shared by others, through comments or the 'like' function. The option to engage using photos and the 'like' function rather than solely using words provided a method of visibility less dependent on cognitive and literacy skills. Awareness of being seen online lead to a sense of belonging, being included and treated 'the same' for some participants. This seemed to be enhanced by the popularity of social media in the general population and a sense of validation from 'likes' or positive comments from others. However, for other participants being seen online led to facing disability stigma due to receiving discriminatory comments and being left out. Participants demonstrated different ways of responding to disability stigma, which seemed

to be influenced by access to/ views of support network and individual differences in appraisal of online content.

1. Navigating the online world

Opportunities

Maintaining relationships

Many participants commented on using social media to keep in touch with family and friends, “I use (Facebook) to contact friends and some family, I have family from my brother in laws side in north, so I use it to keep in contact with them” (Hazel). Participants referenced keeping in contact via sending messages and sharing photos to update family and friends “you can take pictures, say if you go to (name of town), you can take pictures of there, or video and then you can put it on Facebook and share it” (Goldy Girl). Participants commented on how social media facilitated a sense of togetherness during the COVID-19 lockdowns. Speaking from the position of a member of the national LD charity, Sam commented “through social media it’s helped me to connect, to be able to talk to my friends and family over, or through, Facebook. Which I think, quite a few of our members were affected by it, with the lock down n’ stuff”. However, the limitations of connecting via social media were also raised, “it was almost like you were in a prison cell because you had that social media but you couldn’t see people. You could talk to them... but it’s not the same as hearing someone’s voice” (Hazel).

Adam spoke fondly of a group he follows on Facebook which facilitated a sense of connection with his late Grandmother, “they do videos of trains, my Nan used to live right off the back of that Railway...(it makes me feel) young”. Claire echoed the importance of such connections for PWLD, “I think lots of PWLD are really isolated and lonely and so it’s a

way of being connected to groups that you have an interest in". Claire also commented that many people she supports use social media to search for romantic relationships, although this was not raised by the participants. Claire shared an observation that people often have difficulty with understanding that content on social media is not an authentic representation of the offline world. For example, in the case of friend requests, "they get a friend request and people take that very personally, someone's asked to be my friend, so they confirm and then they end up with 700 people on their account, we've talked about that a lot".

Observing others

Many participants reported the opportunity to observe others as an incentive for using social media, "they post things about what they've been up to, going to work, going out with friends, I like to look at what they've been up to, that kind of thing really" (Lorraine). Adam also shared that he enjoyed watching others argue in the comment section of Facebook, "probably the main thing is, like, I like to watch the arguments". For some, observing others seemed to enhance a sense of feeling different, as David highlighted when talking about seeing others in relationships online, "it makes me feel sad and upset when I see them happy, I get sad because they've got a girlfriend and I don't have one". However, Frank shared that seeing people with very different lives is enjoyable to observe and does not elicit any negative feelings, "you can see in people's houses, some rich ones, some poor ones...you can see them going to all the parties." When asked if this ever makes him feel left out, Frank replied "no it's pretty entertaining really, seeing people having a good time". Claire highlighted the role of support networks in helping individuals make sense of what they see online, "some people don't have very good support networks around them, so it's

their only way of education... it's just trying to explain that people don't have perfect lives... we all have good times and bad times, and nobody's lives are like they look on TikTok".

Engaging with interests

Participants reported using social media when feeling bored for entertainment purposes, "it kind of, like, brings entertainment as well... I watch prank videos n' stuff like that" (Hazel). Participants also shared that they use social media to follow their interests, "I'm on a lot of groups sites I am, on Facebook...music and I'm also on train groups, I'm into trains" (Adam). "I follow all the soaps, like Eastenders, Hollyoaks and other things like that" (Lorraine).

Seeking information

Many participants referenced searching friends and information on social media, "searching for what places you want to go, look up friends, add your friends..." (Goldy Girl). Participants also spoke about using social media for news updates, "people update me, things about the world" (Lorraine). Hazel who had recently received a diagnosis of autism, discussed accessing support from an autism page "I went to ask one of my friends from (autism social media page) how they deal with it and how they were diagnosed and stuff like that". Sam also used social media to keep up to date with information regarding her work, "Salvation Army, they've got a website that I follow on Facebook. So it's about work involvement as well as everything else really". Communication abilities appeared to be a mediating factor in the extent to which people were able to access information online. For example, Sam described feeling frustrated at not being able to understand some content on Facebook, "if it's something to do with politics or something, I wouldn't understand it, I'd

get very frustrated because I couldn't understand what it means, I couldn't understand what they were trying to say".

Challenges

Fake news and fake accounts

Many participants commented on the abundance of 'fake news' on social media and the real-world consequences of this, "... it's like the petrol, somebody put it on Instagram the other day and now nobody can get petrol" (Frank). This seemed to elicit confusion as to which news is trustworthy, "I don't know which one to believe sometimes" (Anne). Adam referenced the anonymity of social media and how this can facilitate online hate, "on TikTok, you can make loads of profiles and you can change your name loads of times in a day". Hazel also shared concern about fake profiles online "you don't know whose behind that keyboard...it's a scary thought".

Feeling misunderstood

Participants raised concerns about being misunderstood on social media and also misunderstanding what others write, "I can misjudge letters with words, or you could write something and someone could take it a different way and you don't realise because I don't understand emotion all the time" (Hazel). Claire shared that she often supports people with such misunderstandings on social media, "I think there's often a misunderstanding of how someone has written a message or understood a message and then obviously it can go from one to a million". Adam spoke about trying to reduce the risk of being misunderstood on social media by reading messages back before sending them, "sometimes I write things down for myself first and I think 'how would that look if someone said that to me?'".

Being exploited

Participants raised concerns about private information being stolen on Facebook, “they could try and get all your details from your Facebook” (Sam). Frank had experience of accidentally signing up to subscriptions on social media, “you don’t actually know what you’re pressing actually, you might be pressing something like a lock in, like a Facebook lock in, you’ve got to be very careful”. The potential risks on social media appeared to lead some participants to feel more vulnerable online, “it makes us feel more vulnerable...because you can think ‘oh they’re being nice...they’re sending a friend request’, we had an issue before by a man who sent us a friend request, he was talking to us all nice and polite ... then three days later, he asked me for some money” (Adam). Lorraine also reflected on the impact this has on her general sense of safety online, “you just have that feeling if you don’t know someone, like, are they going to ask me for money or... you just have that feeling in your head”.

Accessibility issues

Experiences of social media were mediated by accessibility of apps and access to appropriate technology. For example, Anne explained the impact of different keyboard styles, “I like the keyboard (of WhatsApp), I find the keys on Chatter, Instagram a bit hard sometimes”. Sam shared that frequent changes to social media app’s design led to frustration, “it’s the changes that make it more confusing for me on social media”. Changes to YouTube regulations also led to frustration for Kayleigh, who ultimately decided to stop creating her own content, “you can get in trouble with the community guideline thing and so I stopped uploading because it got confusing”. Participants shared that they often feel

frustrated when using social media due to not being able to understand content, “all these social medias don’t have nothing in easy read... it gets really, really, frustrating, because you’ve got to sit and try and figure out what it means... like the news for example, I’d like to read it if that makes sense, I do try to, but if I can’t then I just scroll up” (Sam). Participants also expressed frustration at online ‘trolls’ who make abusive or irrelevant comments, “they (trolls) are the most annoying people on the internet... I asked a question about Burger King and some people took my question seriously but others didn’t... you know, they were joking and all that, lots of swearing” (Kayleigh).

Accessibility issues were also raised by Claire, who had seen a significant improvement in access to technology during the COVID-19 pandemic, “although covid was a terrible time, it has helped people get access to a decent phone or tablet, people who never would have had a tablet or iPhone before”. Claire also highlighted the option to send voice notes rather than text messages on WhatsApp and the impact this has on accessibility, “as a support worker, I use that a lot... if people struggle with reading and writing we use that and they can send a voice message back”.

Strategies

Seeking support

Many participants referenced seeking support in relation to accessing social media and navigating online experiences. Opinions and beliefs of support networks appeared to mediate how individuals experienced social media. For example, Claire (support worker) reported that the National LD charity takes a supportive approach towards risk, “if the person can understand the consequences, they’re able to make those choices for themselves... we can only give advice, if we think people are at risk we have to raise a

safeguarding and talk to people about it". Some participants spoke of family members taking a more restrictive or risk averse approach, "my sister decided it's safer for me not to use Facebook" (Nigel). David's family were apparently very supportive of his social media use and his cousin provided direct support, "he sends me the pictures and some writing to put up and I put it on Facebook".

Active avoidance

Participants spoke of mitigating risk on social media by ignoring friend requests from unknown contacts, "I don't accept people like that...if it's my friends or family, I'll accept them" (Goldy Girl).

Assessing

Experiences online appeared to be mediated by skills in assessing the credibility of online content and accounts. For example, participants described assessing profiles for authenticity by looking through profile photos and seeing if they had shared friends, "see what they look like properly. Go through all their photos, go see what age they are and who they are and who their friends are, if they've not got pictures on it, it's fake" (Frank). Adam shared that he challenges people who ask him for money online, "I like to play along with it... just to see are they genuine, even though I'm not giving them money, I just like to see how far they would push someone... then I report it to Facebook". These skills are likely to limit the risk of exploitation online. However, Claire explained that people she supports find this a lot harder if someone befriends them online, "people that we work with say they're not going to give out their address but it's very different if they think that person likes them... we've had a couple of really nasty safeguarding experiences that way".

Being seen online

The process of navigating the online world enabled a sense of being seen by others. This was articulated by Frank when asked why he shares photos on social media, “just showing off really, I like showing off!”. Adam also described enjoying sharing photos of days out and holidays because “it makes people feel jealous”. The feeling of being seen appeared to be facilitated by both being present online and being perceived as present by others.

“Being treated the same”

Adopting a social media presence appeared to facilitate a sense of being the same as non-disabled others “I’d probably say it makes everybody feel the same as well, mostly everyone is on Facebook... we want to be the same as normal people, we don’t want to be separate like we are, know what I mean?” (Frank). For Frank, the option of communicating using pictures rather than words enabled him to be visible online despite his communication difficulties, “I don’t talk with anyone on Facebook anyway, I don’t do that kind of thing. I can spell a little bit but not much. I prefer pictures in my opinion, pictures are better”. Frank spoke openly about social media being a place where he felt included and perhaps free from barriers in his everyday life, “you’re not, like, locked up are you, you’re together when you’re on Facebook and you can see what everyone’s watching, and I think that’s brilliant”. Sense of visibility was also facilitated by receiving responses to shared photos and life events, “we shared on Facebook saying me and my partner got engaged and everyone was saying, like, congratulations and all that. That’s a good thing, what my friends say about me and my partner, that’s one good thing” (Goldy Girl). Frank shared his response to receiving likes on photos of days out he shares, “When I go out visiting, people, places and everything else, I put pictures on Facebook and everyone likes it anyway, everyone likes it”. Participants

also shared feeling a sense of being 'wanted' because of receiving friend requests, "I've got loads of friends... I am so popular, I don't know why!... (it makes me feel) wanted" (Frank).

Facing disability stigma

The visibility afforded by social media led to many facing disability stigma online. For example, Kayleigh who used to enjoy creating YouTube videos stopped following experiences of online hate, "I had a few saying really nasty words like 'oh my god kill yourself', and I had one person saying, 'oh my god you're this old... get a life'". Adam described an incident where a friend posted a video of himself and his wife, Sam, on TikTok, "we got real bad views on us, like, we got told to wear masks and they were saying people with learning disabilities should not be going out on their own". Adam felt the anonymity of social media lead to people being more abusive, "if they see you face to face they would think about how you feel about things, they would put your feelings, like how you feel about things face to face... on the screen they don't think anything else apart from what they think". Frank reflected on the benefit of not being able to read comments, "I like to see who likes my photo's, if they don't like it I don't really know about it. There's pictures of people that liked it, and if they didn't like it you don't notice it so...".

People also referenced feeling left out or marginalised on Facebook because of their disability. Sam spoke about noticing that her employers share the work of other employees and not her own, "it makes me feel like I'm being pushed aside if that makes sense". Adam shared a sense of not feeling accepted, "people shouldn't live worrying about people having learning disabilities, we should all be accepted for who we are. Since the lockdown... we've gone back to so many years ago where we don't get accepted".

Responding to disability stigma

Participants demonstrated individual differences in their responses to stigmatizing experiences online. For example, David's interpretation of discriminatory comments in response to photos he had shared was that others were jealous of him, "It's probably because they're jealous of me... people feel jealous of me because I've got special needs, autism and because they see me talking to my cousins and I've got some friends". However, Kayleigh appeared to feel responsible for the hurtful comments she received in response to her YouTube videos, "I apologised to her, I said 'I have difficulty pronouncing certain words and I'm sorry', but it wasn't good enough for her". Adam, who had received abusive comments in response to a video shared of him on TikTok shared that he managed this by focusing on his own actions, "it doesn't really matter how other people look at you or think of you, as long as you're not hurting no one, you shouldn't worry about other people... what they think, what they say, what they do... is nothing that I need to worry about".

Internalising of stigmatizing experiences

Some participants indicated that perhaps they had internalised some of these stigmatizing experiences, for example Claire had observed people wanting to conceal their learning disability online when searching for romantic relationships, "we have a few members that would like to date someone without a learning disability, they say somebody 'normal'... they say somebody might look at me differently". Some participants spoke about choosing social media platforms where their identity felt less visible, to avoid receiving online hate. For example, Kayleigh preferred sharing artwork online instead of creating YouTube videos, "I thought I might start sharing artwork rather than YouTube because I'm not on the camera, my artwork is but not me as in me. I feel more in the background... if

someone criticises my artwork, I can say well I am working on it but when people were criticising me for my looks or the way I speak it's kind of more hurtful". Participants spoke of censoring themselves online to avoid consequences, "I don't really make comments on anything. I do love hearts for my brother, but I don't comment on anything because I just think that will come back on me" (Adam). Adam also chose not to have a photo of himself as his profile picture, "I don't even have a photo of myself. I just have a photo of a garden, it's a picture of a garden and that's it, so no one can give me hate".

Taking action

Participants spoke of reporting and/ or deleting offensive comments on social media, "I know how to delete them. I delete them if I get any horrible comments" (Adam). However, how empowered people felt to effect change was mediated by the responsiveness of social media platforms, "we reported it, but unfortunately, how far did that report go? You're never too sure how much do TikTok do anything, they never come back, they say to you they will look into it, but they never come back to you and say 'thank you and this is what we are doing'". The responsiveness of social media platforms appeared to influence a sense of safety online, "I feel a bit more safer in those groups because if there is a disagreement I can go to the admin or person that leads the group and complain to them" (Kayleigh).

Discussion

The results are discussed in relation to the existing research. The findings are also discussed in terms of their strengths and limitations. Implications for research and practice are considered.

Links to theory and research

Navigating the online world appeared to raise many opportunities and challenges for participants. The finding that participants used social media for opportunities such as maintaining relationships, seeking information and engaging with interests was in line with uses and gratifications theory (Katz & Blumler, 1974). These findings were also in line with previous research in general (Gray, 2018) and learning disability populations (Chadwick, 2018; Caton and Chapman, 2016). The extent to which participants actively engaged with social media seemed to vary according to their communication abilities and accessibility of social media apps. The opportunity to engage visually, by viewing and sharing photos and videos, appeared to make social media accessible to all participants as it is less reliant on cognitive and communication abilities.

The process of navigating the opportunities and challenges present on social media seemed to lead participants to feel more seen or visible online. For some participants being seen facilitated a sense of inclusion and belonging, however others face very othering and stigmatizing experiences. Previous research has found social media to be a place where PWLD could “be like everybody else” (Löfgren-Mårtenson, 2008) and not need to “mask who they are” (Chadwick & Fullwood, 2018). Whilst one participant did note that he felt “the same” on social media (Frank), many described experiences of feeling very othered on social media. It is of note that Löfgren-Mårtenson’s study was conducted in 2008, when social media was a fairly new phenomenon. Chadwick & Fullwood (2018) referenced participants using Facebook and “the internet”, therefore these participants may not have been exposed to such a vast audience compared with platforms that post publicly (e.g., YouTube and TikTok). A recent report found online hate speech to have risen by 20% since

the start of the COVID-19 pandemic in 2020 (Ditch the Label, 2021), which may have contributed to the difference in findings.

In response to facing stigmatizing experiences, some participants spoke of concealing aspects of their identity and trying to “stay in the background” to avoid such experiences. This form of self-censorship may be suggestive of self-stigmatization and internalisation of discriminatory views (Corrigan et al., 2009). According to identity process theory (Jaspal and Breakwell, 2014), threats to identity occur when information is received that threatens core principles of identity such as self-esteem or self-efficacy. Hiding aspects of the learning-disabled identity may, therefore, be a coping mechanism for managing threats to self-esteem. Additionally, participants spoke of asserting their preferred identities online. For example, in response to seeing her employer share other people’s work online but not her own, Sam spoke of celebrating her progress in a cooking class by sharing photos on her Facebook page. This may be another coping mechanism in order to preserve self-esteem.

All participants demonstrated awareness and concern over the potential risks they are exposed to on social media. External risks such as exploitation and hateful comments led to internal states of vulnerability, frustration and feeling left out. Participants demonstrated skills in mitigating these risks, through seeking support, assessing credibility of friend requests and news content online. However, Claire (support worker, national LD charity) has observed people to be more inclined to forgo these strategies if someone befriends them and can take friend requests on social media very personally. One participant illustrated this when he said receiving friend requests makes him feel “popular” and “wanted” (Frank). This combined with high rates of loneliness and isolation in this population may make PWLD more vulnerable to exploitation online.

However, the ability to engage in risk taking behaviours on social media also provides opportunities, for example, previous research has found social media to be a place where PWLD can explore their identity and sexuality (Darragh et al., 2017). One participant (Frank) referred to not being “locked up” on social media. Perhaps for Frank, social media is a place to explore away from the usual barriers experienced by PWLD in everyday life (e.g., observation of support workers). Frank demonstrated awareness of the risks involved with adding unknown contacts online, however, he did also suggest that he likes to accept requests from females, “you know if it’s a girl on there, if I don’t know her, I might think, oh I’ll push the button anyway”. Claire shared that many people she supports seek romantic relationships on social media, however, most participants did not raise this in the study. The majority of participants were recruited from advocacy groups where risks and rules of social media were discussed, perhaps this led to participants giving more socially desirable answers. The researcher may have also been seen as a professional and therefore elicited more socially desirable responses (Williams, 2021). Perhaps future research would benefit from employing a more collaborative approach to mitigate this effect, such as a participant action design (Balcazar et al., 2006).

Strengths and limitations

This study aimed to build an initial grounded theory model of how PWLD experience social media. The inclusion of PWLD as well as professionals allowed for incorporating multiple perspectives in the model. The researcher intended to draw from a broader pool of participants, including family members, however practical limitations such as the study timeline meant true theoretical sampling wasn’t possible. A limitation of this study is that 8 of the 10 PWLD included were recruited from a national LD charity self-advocacy group. This

may have led to people speaking from the position of an advocacy group member, leading to more socially desirable answers and more focus on risk management. This may also have been the case for the two participants recruited from the NHS service, as they are likely used to professionals giving them advice regarding managing risks. For national LD charity participants, the support worker who facilitates the group was present during the interviews (due to their preference) which may have further exaggerated this effect. The current study did attempt to recruit participants outside of this group through advertising in newsletter disseminated by the national LD charity, however, no responses were received. PWLD who aren't accessing these charity or NHS services may have different experiences of using social media, due to receiving different levels of support and perhaps having different degrees of ability.

A further limitation is that the participant's level of learning disability and other diagnoses were not recorded as part of the demographics. Whilst this may be implicit in the extent to which participants use social media, their living circumstances and occupation, this omission may make it difficult for future studies to compare findings. Of the ten PWLD included in this study, nine identified their ethnicity as white British. Although generalisability of findings is not an objective of qualitative research, it is important to highlight that the experiences described may be specific to this demographic, as ethnicity has been found to influence online experiences (Relia et al., 2019). This is a relatively small sample size and participants were also receiving specialist learning disability services. Therefore, the sample will not be reflective of the wider learning disability population.

Implications for research

This study builds on existing research regarding PWLD and their experience of social media. The study suggests an initial model for understanding how PWLD experience social media and which processes may shape individual experiences. As this is a preliminary model, further research may benefit from further exploring the conclusions made. It would likely be beneficial to incorporate the experiences of other learning-disabled populations, for example, those not in receipt of specialist services, in order to compare findings and broaden understanding. Social media appeared to be a topic commonly raised in the advocacy groups, perhaps future research could benefit from employing a Participatory Action Design, to provide PWLD a more active role in the research (Balcazar et al., 2006).

Implications for practice

The results indicated that social media played a significant part in participants lives and that this significance increased during the COVID-19 pandemic. Experiences on social media appeared to provide both opportunities for belonging and identity expression alongside risk of exclusion and discrimination. Online interactions may be particularly salient for this population as they are at a higher risk of isolation and loneliness (Brown & McCann, 2018; National Development Team for Inclusion, 2019). Findings highlighted the prevalence of exposure to stigmatising experiences within this population, which could increase risk of anxiety and depression (Emerson, 2010; Paterson et al., 2012; Ali et al., 2015). Therefore, it is important to explore social media use with PWLD, as it may hold relevance in both assessment and treatment of mental health difficulties.

The current study found the impact of stigmatizing experiences to be mediated by individual appraisals of online content and interactions. Practitioners may therefore wish to explore how individuals with learning disabilities interpret and relate to online content. This

may have important implications for how people perceive their identities as a person with a learning disability (Jaspal and Breakwell, 2014). If these experiences are internalised, leading to self-stigma, this may affect their self-esteem and motivation to set and work towards goals (Corrigan et al., 2009). Another mediating factor was access to appropriate support. It may be helpful for practitioners to explore the views and approaches of support networks in order to facilitate adaptive social media use. Practitioners may find it helpful to understand what benefits individuals currently gain from using social media as perhaps this could be a useful resource to build upon in treatment.

Finally, many participants referenced seeking support as a strategy for navigating social media. It was clear from the reports of the participants that approaches to social media differed between family members and organisations such as the LD charity. This finding suggests that clinical psychologists may play an important role in providing training for people who support PWLD regarding the risks and benefits of social media, and how to support PWLD in navigating these difficulties. This may help to improve consistency of approach across settings and may reduce the need for restrictive practices, such as not allowing individuals to use social media.

Conclusion

This study aimed to propose a preliminary model of how people with learning disabilities use and experience social media. Through grounded theory analysis of interviews with people with learning disabilities who use social media, themes emerged in relation to social media use, being seen online and facing and responding to disability stigma. The model suggested factors which contribute to the process of navigating the online world, including support networks, accessibility issues and appraisal of online content. These

findings contribute to the body of research regarding how people with learning disabilities experience social media and suggests a framework which could be used by clinicians to explore social media experiences with people with learning disabilities.

References

- Ali, A., King, M., Strydom, A., & Hassiotis, A. (2015). Self-reported stigma and symptoms of anxiety and depression in people with intellectual disabilities: Findings from a Cross Sectional Study in England. *Journal of Affective Disorders, 187*, 224–231. <https://doi.org/10.1016/j.jad.2015.07.046>
- Balcazar, F., Keys, C., & Kaplan, D. (2006). Participatory Action Research and People with Disabilities: Principles and Challenges. *Canadian Journal of Rehabilitation, 12*(2). Retrieved from https://www.researchgate.net/publication/239921190_Participatory_Action_Research_and_People_with_Disabilities_Principles_and_Challenges.
- Barker, D. (1983). How to curb the fertility of the unfit: The feeble-minded in Edwardian Britain. *Oxford Review of Education, 9*(3), 197–211. <https://doi.org/10.1080/0305498830090304>
- Bhaskar, R. (2008). Dialectic: The Pulse of Freedom. *Philosophy of Science, 1*. <https://doi.org/10.4324/9780203892633>
- Bhaskar, R., 2008. A Realist Theory of Science. *Journal of Critical Realism*, [online] pp.46-48. Available at: <http://uberty.org/wp-content/uploads/2015/09/Roy_Bhaskar_A_Realist_Theory_of_Science
- Breakwell, G., & Jaspal, R. (2014). Identity process theory. *Identity Process Theory: Identity, Social Action and Social Change*. <https://doi.org/10.1017/cbo9781139136983>
- Brown, M., & McCann, E. (2018). Sexuality issues and the voices of adults with intellectual disabilities: A systematic review of the literature. *Research in Developmental Disabilities, 74*, 124–138. <https://doi.org/10.1016/j.ridd.2018.01.009>
- Caton, S., & Chapman, M. (2016). The use of social media and people with intellectual disability: A systematic review and thematic analysis. *Journal of Intellectual and Developmental Disability, 41*(2), 125–139. <https://doi.org/10.3109/13668250.2016.1153052>
- Chadwick, D. D., & Fullwood, C. (2018). An online life like any other: Identity, self-determination, and social networking among adults with intellectual disabilities. *Cyberpsychology, Behavior, and Social Networking, 21*(1), 56–64. <https://doi.org/10.1089/cyber.2016.0689>
- Chalghoumi, H., Cobigo, V., Dignard, C., Gauthier-Beaupré, A., Jutai, J. W., Lachapelle, Y., Lake, J., Mcheimech, R., & Perrin, M. (2017). Information privacy for technology users with intellectual and developmental disabilities: Why does it matter? *Ethics & Behavior, 29*(3), 201–217. <https://doi.org/10.1080/10508422.2017.1393340>

- Chatzitheochari, S., Parsons, S., & Platt, L. (2016). Doubly disadvantaged? bullying experiences among disabled children and young people in England. *Sociology*, 50(4), 695–713. <https://doi.org/10.1177/0038038515574813>
- Chiner, E., Gómez-Puerta, M., & Cardona-Moltó, M. C. (2017). Internet use, risks and online behaviour: The view of internet users with intellectual disabilities and their caregivers. *British Journal of Learning Disabilities*, 45(3), 190–197. <https://doi.org/10.1111/bld.12192>
- Corrigan, P. W., & Rao, D. (2012). On the self-stigma of mental illness: Stages, disclosure, and strategies for change. *The Canadian Journal of Psychiatry*, 57(8), 464–469. <https://doi.org/10.1177/070674371205700804>
- Corrigan, P.W., Larson, J., Rusch, N., (2009). Self-stigma and the “Why try” effect: Impact on life goals and evidence-based practices. *World Psychiatry*, 8(2), 75–81. <https://doi.org/10.1002/j.2051-5545.2009.tb00218.x>
- Darragh, J., Reynolds, L., Ellison, C., & Bellon, M. (2017). Let’s talk about sex: How people with intellectual disability in Australia engage with online social media and intimate relationships. *Cyberpsychology: Journal of Psychosocial Research on Cyberspace*, 11(1). <https://doi.org/10.5817/cp2017-1-9>
- Department of Health. (2005). *Mental Capacity Act*. London: HMSO
- Dey, I. (1999) *Grounding Grounded Theory*. San Francisco, CA: Academic Press
- Ditch the Label. (2021). *Uncovered: Online Hate Speech in the Covid Era*. Retrieved 28 February 2022, from <https://www.ditchthelabel.org/research-papers/hate-speech-report-2021/>.
- Emerson, E. (2010). Self-reported exposure to disablism is associated with poorer self-reported health and well-being among adults with intellectual disabilities in England: A cross-sectional survey. *Public Health*, 124(12), 682–689. <https://doi.org/10.1016/j.puhe.2010.08.020>
- Ezumah, B. (2018). College Students’ Use of Social Media: Site Preferences, Uses and Gratifications Theory Revisited. *International Journal Of Business And Social Science*, 4(5). Retrieved 5 March 2022, from http://file:///C:/Users/User/Downloads/college_students_use_of_social_media_published-with-cover-page-v2.pdf.
- Franco, D, G., Cardoso, J., & Neto, I. (2012). Attitudes towards affectivity and sexuality of people with intellectual disabilities. *Sexuality and Disability*, 30, 261-287. <https://doi.org/10.1007/s11195-012-9260-x>
- Glaser, B. G., & Strauss, A. L. (1967). The discovery of grounded theory. *The Discovery of Grounded Theory*, 1–18. <https://doi.org/10.4324/9780203793206-1>

- Glencross, S., Mason, J., Katsikitis, M., & Greenwood, K. M. (2021). Internet use by people with intellectual disability: Exploring digital inequality – a systematic review. *Cyberpsychology, Behavior and Social Networking*, online ahead of print. <https://doi.org/10.1089/cyber.2020.0499>
- Gubrium, J. F., Holstein, J. A., Marvasti, A. B., & Marvasti, K. M. (2012). The SAGE handbook of interview research: The complexity of the craft, second edition. In *The SAGE Handbook of Interview Research: The Complexity of the Craft* (pp. 1-570). SAGE Publications Inc.. <https://doi.org/10.4135/9781452218403>
- Gubrium, J., Holstein, J., Marvasti, A., McKinney, K. (2012). *The SAGE Handbook of Interview Research: The Complexity of the Craft* (2nd ed., pp. 105-111). SAGE Publishing.
- Hogan, B. (2010). The presentation of self in the age of social media: Distinguishing performances and Exhibitions Online. *Bulletin of Science, Technology & Society*, 30(6), 377–386. <https://doi.org/10.1177/0270467610385893>
- Jahoda, A., Wilson, A., Stalker, K., & Cairney, A. (2010). Living with stigma and the self-perceptions of people with mild intellectual disabilities. *Journal of Social Issues*, 66(3), 521–534. <https://doi.org/10.1111/j.1540-4560.2010.01660.x>
- Jenaro, C., Flores, N., Cruz, M., Pérez, M. C., Vega, V., & Torres, V. A. (2017). Internet and cell phone usage patterns among young adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 31(2), 259–272. <https://doi.org/10.1111/jar.12388>
- Katz, E., Blumler, J., & Gurevitch, M. (1974). Uses and Gratifications Research. *Public Opinion Quarterly*, 37(4), 509. <https://doi.org/10.1086/268109>
- Keipi, T., Näsi, M., Oksanen, A., & Räsänen, P. (2016). Online hate and harmful content. *Routledge Advances in Sociology* . <https://doi.org/10.4324/9781315628370>
- Kyland, F., Molka-Danielsen, J., & Balandin, S. (2012). Examining the use of social media tool ‘Flickr’ for impact on loneliness for people with intellectual disability. In *Proceedings of the 2012 Norsk konferanse for organisasjoners bruk av informasjonsteknologi*, Akademika forlag (pp. 253-264). Deakin University. <http://hdl.handle.net/10536/DRO/DU:30062177>
- Laura Gray (2018) Exploring how and why young people use social networking sites, *Educational Psychology in Practice*, 34:2, 175-194, DOI: 10.1080/02667363.2018.1425829
- Livingstone, S., & Davidson, J. (2019). *Adult Online Harms Report*. Assets.publishing.service.gov.uk. Retrieved 20 February 2022, from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/811450/Adult_Online_Harms_Report_2019.pdf.

- Löfgren-Mårtenson, L. (2008). Love in cyberspace: Swedish young people with intellectual disabilities and the INTERNET1. *Scandinavian Journal of Disability Research*, 10(2), 125–138. <https://doi.org/10.1080/15017410701758005>
- Logeswaran S, Hollett M, Zala S, Richardson L, Scior K. (2020). How do people with intellectual disabilities construct their social identity? A review. *Journal of Applied Research Intellectual Disabilities*. 2019;32:533–542. <https://doi.org/10.1111/jar.12566>
- Luo, M., & Hancock, J. T. (2020). Self-disclosure and social media: Motivations, mechanisms and psychological well-being. *Current Opinion in Psychology*, 31, 110–115. <https://doi.org/10.1016/j.copsyc.2019.08.019>
- Magaldi, D., & Berler, M. (2020). Semi-structured Interviews. *Encyclopedia Of Personality And Individual Differences*, 4825-4830. https://doi.org/10.1007/978-3-319-24612-3_857
- Manago, A. M. (2015). Identity development in the digital age: The case of social networking sites. In K. C. McLean & M. Syed (Eds.), *The Oxford handbook of identity development* (pp. 508–524). Oxford University Press.
- Marriot, A. (2019). *The right to a relationship*. National Development Team for Inclusion. Retrieved May 5, 2022, from <https://www.ndti.org.uk/projects/the-right-to-a-relationship>
- NHS Digital (2022). *Learning Disabilities Statistics*. NHS choices. Retrieved May 5, 2022, from <https://digital.nhs.uk/data-and-information/publications/statistical/learning-disability-services-statistics>
- Oyserman, D., Elmore, K., & Smith, G. (2014). Self, self-concept, and identity. In M. Leary & J. Tangney (Eds.), *Handbook of Self and Identity* (2nd ed., pp. 5–10). essay, The Guilford Press.
- Paterson, L., McKenzie, K., & Lindsay, B. (2012). Stigma, social comparison and self-esteem in adults with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 25(2), 166–176. <https://doi.org/10.1111/j.1468-3148.2011.00651.x>
- Relia, K., Li, Z., Cook, S. H., & Chunara, R. (2019). Race, Ethnicity and National Origin-Based Discrimination in Social Media and Hate Crimes across 100 U.S. Cities. *Proceedings of the International AAAI Conference on Web and Social Media*, 13(01), 417-427. Retrieved from <https://ojs.aaai.org/index.php/ICWSM/article/view/3354>
- Seidel, J. and Kelle, U. (1995) Different functions of coding in the analysis of textual data. In: U. Kelle (Ed.), *Computer-aided qualitative data analysis: theory, methods and practice* (pp. 52-61). London: Sage.
- Sheehan, R., & Ali, A. (2017). Self-stigma in People with Intellectual Disabilities . In *Intellectual disability and stigma: Stepping Out from the Margins* (pp. 91–103). essay, PALGRAVE MACMILLAN.

- Szivos-Bach, S. E. (2010). Social Comparisons, stigma and mainstreaming: The self esteem of young adults with a mild mental handicap. *Mental Handicap Research*, 6(3), 217–236. <https://doi.org/10.1111/j.1468-3148.1993.tb00054.x>
- Tufford, L., & Newman, P. (2010). Bracketing in Qualitative Research. *Qualitative Social Work*, 11(1), 80-96. <https://doi.org/10.1177/1473325010368316>
- Urquhart, C. (2013). *Grounded theory for qualitative research: A practical guide*. SAGE.
- Vogel, D. L., Wade, N. G., & Hackler, A. H. (2007). Perceived public stigma and the willingness to seek counseling: The mediating roles of self-stigma and attitudes toward counseling. *Journal of Counseling Psychology*, 54(1), 40–50. <https://doi.org/10.1037/0022-0167.54.1.40>
- Wasserman, D. (2019), “A case for greater risk tolerance in internet use by adults with intellectual disabilities: a comment on Chalghoumi et al.”, *Ethics & Behaviour*, pp. 1-4, doi: 10.1080/10508422.2018.1522256.
- Whiting, A., & Williams, D. (2013). Why people use social media: a uses and gratifications approach. *Qualitative Market Research: An International Journal*, 16(4), 362-369. <https://doi.org/10.1108/qmr-06-2013-0041>
- Williams, P. (2021). Ethical Considerations and Dilemmas when Undertaking ‘Inclusive’ Research with Vulnerable People. *International Journal Of Pedagogical Advances In Technology-Mediated Education*, 2(2).
- Yardley, L. (2016). Demonstrating the validity of qualitative research. *The Journal of Positive Psychology*, 12(3), 295–296. <https://doi.org/10.1080/17439760.2016.1262624>

Section C: Appendices

Appendix 1: Qualitative Checklist, Critical Appraisal Skills Programme (Singh., 2013)

	Study number and authors	2. Chadwick & Fullwood (2018)	3. Barlott et al., (2020)	6. Shpigelman (2016)	10. Bayor et al., (2019)	14. Lines et al., (2020)	7. Barlott & Torres (2021)
	Study design	Thematic analysis	Thematic analysis	Thematic analysis	Grounded theory	Thematic analysis	Post-qualitative analysis
Section A.	Was there a clear statement in terms of the aims of the research?	Yes	Yes	Yes	Partially	Yes	Yes
Are the results valid?	Is a qualitative methodology appropriate?	Yes	Yes	Yes	Yes	Yes	Yes
	Was the research design appropriate to address the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes
	Recruitment appropriate?	Partial. No reporting of inclusion criteria, why recruitment strategy was chosen or any issues e.g. people deciding not to	Yes	Yes	Partially. No discussion around recruitment strategy.	Yes	Yes

		take part					
	Was the data collected in a way that addressed the research issue?	Partial. Topic guide for interview provided. No mention of setting or saturation of data.	Partial. Interview guide provided. No mention of setting or saturation of data.	Yes	Yes	Yes	Yes
	Has the relationship between researcher and participants been adequately considered?	No mention of researcher bias and influence or how the researcher responded to events during the study.	No mention of researcher bias and influence or how the researcher responded to events during the study.	Yes	No	Yes	Yes
Section B. What are the results?	Have ethical issues been taken into consideration?	Partially. Questions were structured according to participant need and interviews were carried out using the Facebook chat function if needed. However, no mention of capacity or consent issues. No mention of ethical approval.	Partially. No mention of capacity or informed consent but some participants were accompanied by support workers to provide literacy support. Ethical approval processes reported.	Yes	No	Partially. Ethical approval is recorded but there is no mention of issues of consent relevant to the sample.	Yes

	Was the data analysis sufficiently rigorous?	Partially. Stages of analysis reported but no mention of researcher bias.	Partially. Stages of analysis reported but no mention of researcher bias.	Yes	No. No discussion of data analysis process.	Yes	Yes
	Is there a clear statement of findings?	Yes	Yes	Yes	Yes	Yes	Yes
Section C.	Will the results help locally?	Yes	Yes	Yes	Yes	Yes	Yes
	Study number and authors	8. Williams (2019)	9. Ramsten et al., (2020)	11. Heitplats et al., (2020)	13. Buijs et al., (2016)	15. Darragh et al., (2017)	
	Study design	Framework analysis	Content analysis	Content analysis	Case vignette	IPA	
Section A.	Are the results valid?	Yes	Yes	Yes	Yes	Yes	
	Was there a clear statement in terms of the aims of the research?	Yes	Yes	Yes	Yes	Yes	
	Is a qualitative methodology appropriate?	Yes	Yes	Yes	Yes	Yes	
	Was the research design appropriate to address the aims of the research?	Partially. No justification provided for method chosen	Yes	Yes	Partially. No justification provided for method chosen.	Yes	
	Recruitment appropriate?	Partially. No mention of	Yes	Partially. No mention of inclusion/	Partially. No mention of how participants	Yes	

		inclusion/ exclusion criteria		exclusion criteria		were selected or why they were the most appropriate to access the knowledge sought by the study	
	Was the data collected in a way that addressed the research issue?	Partially. No mention of interview guide or justification for method chosen	Yes	Yes	Yes	Partially. No justification of method chosen.	Yes
	Has the relationship between researcher and participants been adequately considered?	No	Yes	Yes	No		Yes
Section B. What are the results?	Have ethical issues been taken into consideration?	No	Yes	Yes	No		Yes
	Was the data analysis sufficiently rigorous?	Partially, no description of analysis process and no mention of researcher bias	Yes	Yes	No		Yes
	Is there a clear statement of findings?	Yes	Yes	Yes	Yes		Yes
Section C. Will the results help	How valuable is the research?	Partially. No mention of implications for	Yes	Yes	Yes		Yes

locally?

future research.

Appendix 2: Quality Assessment Tool for Before-After (Pre-Post) Studies With No Control

Group (NHLBI, 2013)

	1. Davies et al., (2015)
1. Was the study question or objective clearly stated?	Yes
2. Were eligibility/selection criteria for the study population prespecified and clearly described?	No
3. Were the participants in the study representative of those who would be eligible for the test/service/intervention in the general or clinical population of interest?	Yes
4. Were all eligible participants that met the prespecified entry criteria enrolled?	N/A (no entry criteria described)
5. Was the sample size sufficiently large to provide confidence in the findings?	No
6. Was the test/service/intervention clearly described and delivered consistently across the study population?	Yes
7. Were the outcome measures prespecified, clearly defined, valid, reliable, and assessed consistently across all study participants?	Yes
8. Were the people assessing the outcomes blinded to the participants' exposures/interventions?	No
9. Was the loss to follow-up after baseline 20% or less? Were those lost to follow-up accounted for in the analysis?	N/A (no follow-up, pre/post completed in same session)
10. Did the statistical methods examine changes in outcome measures from before to after the intervention? Were statistical tests done that provided p values for the pre-to-post changes?	Yes
11. Were outcome measures of interest taken multiple times before the intervention and multiple times after the intervention (i.e., did they use an interrupted time-series design)?	No
12. If the intervention was conducted at a group level (e.g., a whole hospital, a community, etc.) did the statistical analysis take into account the use of individual-level data to determine effects at the group	N/A

level?

Appendix 3: Quality Assessment tool for Survey studies

	4. Shpigelman & Gill (2014)	5. Kim & Lee (2020)
Was the problem or phenomenon under investigation defined, described, and justified?	Yes	Yes
Was the population under investigation defined, described, and justified?	Yes	Yes
Were specific research questions or hypotheses stated?	Yes	Yes
Were operational definitions of all study variables provided?	Yes	Yes
Were participant inclusion criteria stated?	Yes	Yes
Was the participant recruitment strategy described?	Yes	Yes
Was a justification/rationale for the sample size provided?	No	Yes
Was the attrition rate provided? (applies to cross-sectional and prospective studies)	N/A	N/A
Was a method of treating attrition provided? (applies to cross-sectional and prospective studies)	N/A	N/A
Were the data analysis techniques justified (i.e., was the link between hypotheses/aims/research questions and data analyses explained)?	Yes	Yes
Were the measures provided in the report (or in a supplement) in full?	Yes	Yes
Was evidence provided for the validity of all the measures (or instrument) used?	No	Yes
Was information provided about the person(s) who collected the data (e.g., training, expertise, other demographic characteristics)?	No	Yes
Was information provided	Yes	Yes

about the context (e.g., place) of data collection?		
Was information provided about the duration (or start and end date) of data collection?	No	Yes
Was the study sample described in terms of key demographic characteristics?	Yes	Yes
Was discussion of findings confined to the population from which the sample was drawn?	Yes	Yes
Were participants asked to provide (informed) consent or assent?	Yes	Yes
Were participants debriefed at the end of data collection?	No	No
Were funding sources or conflicts of interest disclosed?	Yes	Yes

12. Chiner et al., (2017)	
1. Was the research question or objective in this paper clearly stated?	Yes
2. Was the study population clearly specified and defined?	Yes
3. Was the participation rate of eligible persons at least 50%?	No. 14% family members, 25% PWLD and 56% staff members
4. Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?	Participants selected from same time period. No mention of inclusion/exclusion criteria
5. Was a sample size justification, power description, or variance and effect estimates provided?	No
6. For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?	No
7. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?	No (cross-sectional study, data collected at same time point)
8. For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g., categories of exposure, or exposure measured as continuous variable)?	No.
9. Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?	Yes



10. Was the exposure(s) assessed more than once over time?	No
11. Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?	Yes
12. Were the outcome assessors blinded to the exposure status of participants?	No
13. Was loss to follow-up after baseline 20% or less?	N/A
14. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?	No




Appendix 5: Accessible information sheet


Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG
www.canterbury.ac.uk/appliedpsychology




Summary information sheet

A grounded theory of the experience of social media use in adults with learning disabilities.

	<p>Hello. My name is Megan Montgomery and I am a trainee clinical psychologist at Canterbury Christ Church University.</p> <p>I would like to invite you to take part in a research study.</p>
	<p>Research studies help to find answers to questions. They also help to improve health care services.</p> <p>This research study will help us to understand how people with learning disabilities use social media, and how they can be best supported to use social media.</p>

 <p>shutterstock.com • 182245769</p>	<p>You have been invited to take part in this study because you use social media.</p> <p>We may also ask to speak with your family/ carer or healthcare professionals about social media.</p> <p>There will be around 20 other people in this study.</p>
	<p>It is your decision to take part in this study.</p> <p>If you say no, it will not affect the care you receive.</p> <p>If you say yes, you can still leave the study at any time.</p> <p>You can speak with your family, friends, carers or professionals about this decision.</p>
	<p>If you say yes to taking part in the study, I will invite you to an interview. The interview can be online via video link or at Queen Mary's Hospital in Sidcup.</p> <p>I will ask you questions about how you use social media, the good and bad things about it.</p> <p>This interview will be no longer than</p>

	<p>1 hour.</p> <p>I may contact you after this interview to make sure I have understood what you said.</p> <p>I may also contact you to ask for your thoughts on the study's findings.</p>
	<p>These interviews will be recorded. No pictures or video will be recorded, only sound.</p> <p>These recordings will be written up into a 'transcript'. I will only share the transcript with my supervisor.</p> <p>Some things that you say may be written in the report of the study.</p> <p>I will not share your name or other personal details, to protect your identity.</p> <p>I may have to share what you tell me with other professionals if I feel you or someone else may be in danger.</p> <p>The recordings of the interviews will be kept securely. At the end of the study, we will save some of the data in case we need to check it. We will follow all privacy rules.</p>

	<p>A good thing about taking part in this study is that it will help us to understand how people with learning disabilities use social media.</p> <p>This may help us to understand how people with learning disabilities can be supported to use social media.</p>
	<p>A difficult thing about taking part in this study is that the interviews may lead to talking about difficult topics.</p> <p>It is important to know that you can choose not to answer any questions.</p> <p>You can also choose to take a break or end the interview if you are feeling uncomfortable.</p>
	<p>If you need to make a complaint during the study please contact me using the above number and email address.</p> <p>If the complaint is about me, then you can ask to speak to Dr Fergal Jones (Clinical Psychology Programme Research Director) using his email address: fergal.jones@canterbury.ac.uk</p> <p>You can also speak to your family, carers or professional if this would be helpful.</p>



If you decide to take part in this study, we will give you a £10.00 voucher to say thank you.

We will also pay for your travel costs up to £10.00

Thank you for reading this information sheet.

If you would like more information about the study, you can leave a message for me (Meg Montgomery) on 01227 927070. Please leave your name and number so I can get back to you.

You can also email me at:

m.montgomery1114@canterbury.ac.uk

Appendix 6: Coded transcript

This has been removed from the electronic copy

Appendix 7: Confirmation of ethics approval from Canterbury Christ Church University

This has been removed from the electronic copy

Appendix 8: NHS Health Research Authority Letter of Approval

This has been removed from the electronic copy

Appendix 9: Informed consent questions

Consent will be sought from all participants. Prior to participating in the study, the researcher will read through the information sheet with each participant and check understanding by asking the participants about what was said in the information sheet. The following questions will be asked to determine if the participant is giving informed consent:

1. What will I be talking to you about?

Scoring: 1 = partial description of study. 0 = An irrelevant or vague answer

2. How long will I be talking to you for?

Scoring: 1 = A valid approximation of time is given. 0 = No answer given/ completely wrong answer.

3. Can you tell me any good things about talking to me?

Scoring: 1= An answer with some face validity (e.g. 'help other people to understand). 0= No explanation or completely wrong answer.

4. Can you tell me any bad things about talking to me?

Scoring: 1= An answer with some face validity (e.g. it will make me sad). 0= no answer or irrelevant answer.

5. What can you do if you decide you don't want to talk to me anymore?

Scoring: 1= Understanding that they can withdraw at any stage. 0= no understanding that they can withdraw at any stage.

6. What can you do if you have any questions about the project?

Scoring: 1= Understanding that they can ask questions. 0= No understanding that they can ask questions.

7. Will I talk to anyone else about what you say?

Scoring: 1= Answer indicating some understanding of confidentiality. 0= no understanding of confidentiality.

8. Are you happy to carry on talking with me as part of the project?

Scoring: 1= Answer indicating they are happy to continue. 0= answer indicating they are not happy or no answer.

Participants will be supported to understand the information in the information sheet. Scores of 1 will be required on all questions in order to qualify as informed consent. If after two attempts the participant is not able to give sufficient evidence of informed consent, their participation in the study will be terminated at that point.

Consent forms will be used to record consent for all participants.

What is consent?

- Consent means agreeing to something.
- You have been invited to take part in a research project called ‘the experience of social media use in adults with learning disabilities’
- By ‘social media’ we mean any website or app that you use to connect with other people. Some examples are Facebook, Instagram or YouTube.
- This form is to make sure you agree to part in this study.

Research study consent form

Name of researcher Meg Montgomery

Name of research study The experience of social media use in adults with learning disabilities

Please answer yes  or no  to the following:



I have read and understand the information sheet for the above study.



I have had a chance to think about this decision and ask questions about it

I understand that it is my decision to take part in this study and that I can say 'no' and leave the study at any time.

I understand that saying 'no' will not affect the care I receive



I understand the study will involve meeting with the researcher (Meg Montgomery) for an interview where I will be asked questions about my experience of social media

I understand that the interviews will be recorded and will be listened to by the lead supervisor (Dr Alex Hassett)

I understand that some of my words may be used in the write up of this study and this may be published. None of my personal information such as my name or address will be used, to protect my privacy

I agree for what I say to be used in other research studies in the future, as long as confidentiality is protected.

Consent agreement

This form is to check if you are happy to take part in the research

study

I can give consent by:



Writing



Speaking

You or staff can put a tick  next to the right box.



I understand what taking part in the research study involves

I **agree** to take part in the research study



I understand what taking part in the research study involves

I **do not** want to take part in the research study.



I **do not understand** what taking part in the research study involves

Name of participant.....

Date.....

Name of person taking consent.....

Date.....

Appendix 11. Interview schedule

Research questions

- a. What barriers limit adults with learning disabilities from utilising social media?
- b. What factors enable adults with learning disabilities to use social media?
- c. What is gained from social media use?
- d. What difficulties arise through social media use?
- e. How has social media effected the experience of stigma/ self-stigma?

Interviews people with learning disabilities

- Do you use social media
- What types of social media do you use?
- How long have you been using it for?
- What types of things do you do on ?(whatever social media platform is used)
- What do you like about using ****?
- What do you dislike about it?
- Do you find **** easy to use? What is easy or difficult about it?
- What do you feel **** has added to your life?
- Have you had any difficult times whilst using ***? Please can you tell me a bit more about that?
- Do you think there are any risks from using ***? What are they?
- Have you ever felt at risk? What did you do about it?
- What would you do in the future if you were to feel at risk?
- Do your family members or carers know that you use ***? What do they say about it?
- Do you use any sites that are only for people with learning disabilities? What do you think about this?
- Do you connect with others with learning disabilities online? What do you like or dislike about this?
- Some people with learning disabilities experience being discriminated against because of their disability. Is this something you have experienced? Do you notice this happening to you online? Please could you tell me a bit more?
- Do you think social media has changed your view of learning disabilities? If so, how?

- Do you feel different about yourself online compared with real life? If so, how?
- Is there anything you would like to be different about social media?
- Do you feel you would like more help with using social media? If so, please can you tell me more
- Do you feel your family and/or carers/ staff could be more helpful in supporting you to use social media? If so, in what way?

Family/carers/ professionals interview

- Does (name) use social media? If so what sites do they use?
- How involved are you with (names) social media use?
- What do you feel (name) gains from social media use
- Have any difficulties arisen from social media?
- How easy or difficult do you think using social media is for (name)?
- What do you think contributes to this being easy or difficult?
- What barriers do you think there are to (name) using social media?
- How do you support (name) to use social media?
- What do you think are the possible risks of (name) using social media?
- Have they ever been at risk in this way? If so, what happened? Has this changed the persons relationship with social media? If so, in what way?
- Do you do anything to help reduce the chances of this occurring again?
- Are you aware of (name) facing any stigma online? Would you be able to tell me more about this?
- Do you feel their experience of stigma is different online compared with in real life? If so, in what way?
- Are you aware of how (name) presents themselves online? If so, do you feel (name) presents themselves differently online as compared with in real life? If so, in what way?
- How do you feel about supporting (name) to use social media? Do you feel you need any more help with this?
- If so, what areas do you feel you need more help with and what would you find helpful?

Appendix 12. End of study form

This has been removed from the electronic copy

Appendix 13.

Table illustrating which papers each theme was identified in.

Theme	Papers theme occurred in
Feelings and attitudes towards social media	Shpigelman & Gill, 2014; Shpigelman, 2016; Williams, 2019; Ramsten et al., 2020; Barlott & Torres, 2021.
Opportunities: Independence and autonomy	Shpiegleman & Gill, 2014; Chadwick & Fullwood, 2018.
Opportunities: Developing and expressing identity	Shpigelman, 2016; Shpigelman & Gill, 2014; Chadwick & Fullwood, 2018; Barlott et al., 2020; Williams, 2019.
Opportunities: Connection and belonging	Barlott et al., 2020; Darragh et al., 2017; Chadwick & Fullwood, 2018; Ramsten et al., 2020; Heitplats et al., 2020; Shpigelman, 2016.
Challenges	Shpigelman & Gill, 2014; Shpigelman, 2016; Williams, 2019; Heitplats et al., 2020; Ramsten et al., 2020; Davies et al., 2015; Chiner et al., 2017; Chadwick & Fullwood, 2018; Shpigelman, 2016). Buijs et al., 2017.
Support networks	Chadwick & Fullwood, 2018; Shpigelman, 2016; Ramsten et al., 2020; Heitplats et al., 2020; Chiner et al., 2017; Lines et al., 2020; Darragh et al., 2017; Williams, 2019; Barlott et al., 2020; Bayor et al., 2019.