

**The Use of Social Media and People with Intellectual Disability: A Systematic
Review and Thematic Analysis**

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Abstract

Background: This paper presents a systematic review of the evidence on the use of social media by people with intellectual disability.

Method: Ten primary studies published in the English language between January 2000 and June 2014 were identified from electronic database searches (CINAHL, PsychInfo, Pubmed, Web of Knowledge and Scopus), correspondence with experts and citation tracking.

Results: Nine themes were identified through thematic analysis of the texts: 'safety and safeguarding', 'social identity', 'level of usage', 'support', 'relationships', 'happiness and enjoyment', 'communication and literacy skills', 'cyber-language and cyber-etiquette' and 'accessibility/design'.

Conclusion: Examination of these themes revealed that some people with intellectual disability are having positive experiences using social media in terms of friendships, development of social identity and self-esteem and for enjoyment. However barriers that stop people with intellectual disabilities from successfully accessing social media were identified as being: safeguarding concerns, difficulties caused by literacy and communication skills, cyber-language, cyber-etiquette and accessibility (including lack of appropriate equipment).

Keywords: Internet, intellectual disability, learning disability, social media, systematic review, developmental disability

Introduction

The term 'social media' broadly refers to participative internet use, but has been more formally defined as being characterized by "a group of Internet-based applications that build on the ideological and technological foundations of Web 2.0 and that allow the creation and exchange of user-generated content" (Kaplan & Haenlein, 2010, p. 61). Social media includes blogs, social networking sites (e.g. Facebook), virtual social worlds (e.g. Second Life), collaborative projects (e.g. Wikipedia), content communities (e.g. YouTube) and virtual game worlds (e.g. World of Warcraft) (Kaplan & Haenlein, 2010).

The popularity of social media has been growing steadily and, with the creation of Facebook in 2004, the use of social networking sites significantly increased. Indeed, in the United States, 87% of adults use the internet (Fox & Rainie, 2014) and between 2005 and 2013 the use of social networking sites by online adult users increased from 8% to 73% (Pew Internet Project, 2014). In Australia, by 2012–13, 83% of people over the age of 15 were internet users and social networking was the second most popular use of the internet with 66% of internet users using social networking sites (Australian Bureau of Statistics, 2014). In the UK in 2012, approximately 48% of all adults and 87% of adults aged between 16 and 24 used social networking sites (Office for National Statistics, 2010).

The use of online social networking has been linked to the formation and maintenance of social capital; the benefits a person receives from their relationships with other people, at an individual and community level (Steinfeld, Ellison & Lampe, 2008). It has been argued that social networking services will lead to new forms of social capital, increasing the potential to develop loose connections between

individuals who may provide each other with useful information or new perspectives but typically not emotional support (bridging social capital) (Steinfeld et al., 2008). There is also increasing evidence that “social network sites like Facebook in particular, may be associated with a person’s sense of self-worth and other measures of psychosocial development” (Steinfeld et al., 2008, p. 435). Social networking sites can be used to construct social identity (Barker, 2009; Matsuba, 2006; Salimkhan, Manago & Greenfield, 2010) and people can choose what aspects of their identity they wish to project to others (Ellis, 2010). This can mean that using social networking sites may be beneficial for people with low self-esteem and low life satisfaction (Ellison, Steinfield, & Lampe, 2007).

Social Media and People with Intellectual Disability

The use of social media has the potential to benefit people with intellectual disability in a range of ways. Research evidence shows that people with intellectual disability are at high risk of social isolation and loneliness and often have smaller social networks that consist primarily of family members and support staff (Emerson & McVilly, 2004; Gravell, 2012; Robertson et al., 2001). It is possible that access to social media sites could enable people with intellectual disability to increase the frequency and quality of their social interactions, develop meaningful relationships and reduce feelings of loneliness (Chadwick, Wesson & Fullwood, 2013). Social media can play an important role in supporting the empowerment and participation of individuals and groups by enabling networking, improving self-esteem (Moreno & Kolb, 2012), and enabling online campaigning among marginalized groups such as disabled people (Bowker & Tuffin, 2002).

Research has shown that people with intellectual disability can be supported to use the internet within their everyday lives (Hegarty & Aspinall, 2006; Näslund & Gardelli,

2012). There has been a recent growth in social networking services specifically for people with intellectual disability. These services are typically considered safer and more accessible than sites that have been developed for the wider community. Organisations of and for people with intellectual disability are increasingly using social media tools including blogs, forums, Facebook and Twitter.

However, there is increasing awareness of the 'digital divide'; inequalities in internet access for those who lack either the skills or the opportunity to access internet technology or who are in unequal positions in terms of its use (Mäkinen, 2006). Evidence indicates that people with intellectual disability are less likely than the general population to have access to computers or the internet, and therefore social media (Guo, Bricout & Huang, 2005; Fox, 2011; National Telecommunications & Information Administration and Economic & Statistical Administration, 2013; Office for National Statistics, 2013). Barriers to internet access for people with intellectual disability include financial and economic; societal attitudes and social exclusion; lack of government policy or strategy; support, educational and training barriers (for example, carers' expertise, time and attitudes); individual cognitive, physical and sensory impairments; the complexity of existing devices and internet sites: and the lack of involvement of people with intellectual disability in usability studies (Chadwick, Wesson & Fullwood (2013); Hoppestad, 2013; McKenzie, 2007). These barriers link back to the concept of social capital which can also be conceived in negative terms when non-group members are excluded from having access to the same benefits as members (Steinfeld et al., 2008).

The evidence on the use of ICT (information and communication technology) by people with intellectual disability has already been explored (Chadwick, Fullwood & Wesson, 2013; Chadwick, Wesson & Fullwood, 2013). However, with the rising and

constantly changing use of social media, it is timely to review the literature around social media use by people with intellectual disability. This review aimed to identify and analyse the research evidence on how social media is used and experienced by people with intellectual disability.

Method

The review followed the process set out by the Centre for Reviews and Dissemination (2009). The following databases were searched in June 2014: CINAHL, PsychInfo, Pubmed, Web of Knowledge and Scopus using the following search strategy:

- 1) (learning AND disab*) OR (mental* AND retard*) OR (intellectual* AND disab*) OR (developmental* AND disab*) AND internet
- 2) (learning AND disab*) OR (mental* AND retard*) OR (intellectual* AND disab*) OR (developmental* AND disab*) AND “social media”

In addition, citation tracking and checking of references from journal articles identified by the search were conducted and authors were contacted to determine whether they were aware of any other publications relating to social media.

Papers were included if they described a primary research study exploring the use of social media by people with intellectual disability (children and adults) and if they were published in an English language peer reviewed journal between 2000 (the advent of Web 2.0) and June 2014 (the date of the search). No study design restrictions were applied. Papers were excluded if people with intellectual disability formed less than 75% of the sample or if papers touched on the use of social media as part of a broader study on the use of ICT or the internet by people with intellectual

disability. These two exclusion criteria were implemented after papers were revealed during the search which focussed on people with special education needs (but with only a small percentage of people with intellectual disability) or which focussed broadly on internet use. Seventy-five percent was chosen to ensure the papers' main findings were relevant to research related to people with intellectual disability.

An initial screen of the titles and abstracts of the studies identified by the search was carried out by the first author to determine eligibility. The first and second authors then independently evaluated the full texts of 'relevant' and 'unclear' papers.

Decisions about whether to include the 'unclear' papers (e.g. papers without 100% of participants with intellectual disability) were made by discussion and reassessment of the exclusion criteria.

Figure 1 gives details of the selection process.

+++++Insert Figure 1 about here+++++

Critical Appraisal and Data Extraction

The tools produced by CASP (critical appraisal and skills programme) at the Public Health Resource Unit (2007) were used to guide critical appraisal of the quality of included studies. These tools provide a structured approach for reviewers to consider the appropriateness of study design, risk of bias, choice of outcome measures, recruitment, sample, follow-up, findings and generalisability. A template was designed to extract information on study aims, social media service, sample characteristics, methods, setting and key findings.

In terms of methodologies, the papers included methods that would often be considered low quality (e.g. McClimens & Gordon, 2008, 2009) and were even only partially described (e.g. Holmes & O'Loughlin, 2014). The authors took the decision to be lenient in inclusion in the review because existing research in the area of social media use for people with intellectual disability is so small that it was felt to be important to include studies that added value to the discussion of the experiences of people with intellectual disability.

Analysis

The studies used either questionnaires or qualitative methods such as case studies and interviews. A thematic analysis was therefore appropriate to use and was carried out to describe and compare the main findings. A theoretical approach to thematic analysis was taken (Braun & Clarke, 2006) whereby coding was specifically related to use and experience of social media. Themes were identified to capture important patterns across and within the ten papers. The process followed an adapted version of Braun and Clarke's (2006) 6-phase guide. As there were only ten papers included in the review, both authors followed these steps. Initially, we familiarised ourselves with the ten papers, making notes of initial ideas for codes and themes. At this stage, we then incorporated Webster and Watson's (2002) 'concept matrix' as a way to record emerging themes. This method of analysis provides structure and helps to clarify the concepts from a review (Webster & Watson, 2002). Discussion took place between the two authors to finalise themes; the agreement reached between the two authors provides robust data but as with all qualitative research, the findings are

not necessarily replicable because as Braun and Clarke (2006) point out “researcher judgement is necessary to determine what a theme is” (p.10).

Results

Ten studies fulfilled the review inclusion criteria; an overview of the studies is provided in Table 1. The main focal points of the ten studies that were included were: mobile telephone and internet usage and cyber bullying (Didden et al., 2009); use of blogs (McClimens & Gordon, 2008, 2009); online photo sharing (Kydland, Molka-Danielsen & Balandin, 2012); use of a prototype symbol based communication platform (Keskinen, Heimonen, Turunen, Rajaniemi & Kauppinen, 2012); use of ‘home pages’ (Seale, 2001; Seale, 2007; Seale & Pockney, 2002) and use of popular social networking sites (Holmes & O’Loughlin, 2014; Löfgren-Mårtenson, 2008).

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Methods - The methods used were: questionnaires (Didden et al, 2009), case studies / vignettes (Holmes & O’Loughlin, 2014), interviews (Löfgren-Mårtenson, 2008), both interviews and questionnaires (Keskinen et al, 2012; Kydland, 2012), participant observation and field notes (McClimens & Gordon, 2008, 2009) and thematic analysis of existing online material (Seale, 2001; Seale, 2007; Seale & Pockney, 2002).

Participants - The studies varied greatly in how much demographic detail was provided about the participants; for instance McClimens and Gordon (2008, 2009) included very little, only referring to participants as “adults living with intellectual disability”. However, all of the papers included young people (students) and/or adults with intellectual disability. Participants had a range of communication, literacy, cognitive and ICT skills. In the Seale (2001, 2007) and Seale and Pockney (2002)

papers, participants were referred to as having Downs Syndrome, but in all other papers, participants had a label of intellectual disability/learning disabilities. The reported degree of disability is detailed in Table One. It is somewhat difficult to effectively examine this due to differences in terminology (e.g. Keskinen et al (2012), have rated participants' degree of disability as 'low', 'medium', and 'high' compared to Holmes and O'loughlin's (2014) description of "mild learning disability" and "learning disability") but participants overall were likely to be those with milder disabilities, those who expressed an interest in the research and who were able to take part in tasks requiring some IT skills.

Kydland et al (2012) included participants aged 20-56, but in all of the other studies (where detailed) participants were under 40. Didden et al's (2009) participants were aged 12-19, Holmes and O'Loughlin's (2014) were aged 25-30, Keskinen et al's (2012) were aged 14-37, and Löfgren-Mårtenson's (2008) were aged 18-31. Seale (2001, 2007) and Seale and Pockney's (2002) participants were an average age of 18.

The largest study was Didden et al (2009) with 114 participants. All of the other studies were on a much smaller scale. Participant numbers (where given) were: three (Holmes & O'Loughlin, 2014), nine (Keskinen et al, 2012), twelve (Kydland et al, 2012), ten people with intellectual disability and 12 staff members (Löfgren-Mårtenson, 2008) and 20 (Seale 2001, 2002, 2007).

Participants were from the United Kingdom, Finland, Norway, the Netherlands, Sweden, Japan and Australia.

Themes

The concept matrix in Table 2 shows the main themes identified in this review.

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Braun and Clarke (2006) assert that the number of instances of a theme does not necessarily mean the theme itself is more crucial. However, for the purpose of reviewing current literature and current thinking about social media use, we have adopted an order for discussion based on number of instances of a theme.

Safety and Safeguarding Concerns

The potential risks associated with social media usage and different attitudes towards safety and safeguarding concerns were discussed within eight of the 10 papers.

Holmes and O’Loughlin (2014) and Löfgren-Mårtenson (2008) identified threats to the safety of participants that developed as a result of some of the cyber-language and cyber-etiquette issues presented below. They refer to incidents of both financial and sexual threats (Holmes & O’Loughlin, 2014) and use of pornographic images and films (Löfgren-Mårtenson, 2008). Löfgren-Mårtenson (2008) put forward the views of young people with intellectual disability who were mostly confident and experienced in their use of a Swedish social networking website. However, although participants were aware of the dangers and knew about safety precautions to follow when meeting strangers ‘in real life’, some of the young people mentioned arranging dates in their homes and disclosing personal information online (Löfgren-Mårtenson, 2008).

Safety concerns were also related to concerns about cyber-bullying through social media. This was discussed in two of the papers (Didden et al., 2008, Holmes & O’Loughlin, 2014). Didden et al. (2009) explored cyber-bullying in special education settings in the Netherlands and found that that most students were not involved in

bullying via the internet (90%) or cellphone (86%) during the previous month. However, 5-12% of participants said they were victimized at least once a week (depending on the form of victimization). Although only a small sample, Holmes and O'Loughlin (2014) also found that two of their three participants had encountered cyber-bullying including unwanted messages, personal remarks about their appearance and activities and unwanted sharing of private and personal information online. Although her study did not focus on cyber-bullying, Seale (2007) describes how one personal home page had been shut down by the person's mother "due to some nasty and sick people on the internet" (p. 182), indicating that offensive comments had been made by other people online.

There was some evidence that family members and people who work with people with intellectual disability sometimes banned certain sites (e.g. those with pornographic or violent content) or monitored the use of social media and posting of information (Löfgren-Mårtenson, 2008; Seale, 2007). For support workers and family members "a conflict of interest may occur when the facilitation of independence clashes with their (parental or) professional role" (Seale 2007, p. 182). These fears of safety can influence the support that family members may be willing to provide (Seale, 2007). Seale (2001) identified that support to participate in social media from family members was common and suggests that this may be due to family members wanting to influence how much content is revealed and to ensure safety.

The understanding and perceptions of risk by people with intellectual disability may differ to that of family carers and clinicians (Holmes & O'Loughlin, 2014; Löfgren-Mårtenson, 2008). Löfgren-Mårtenson (2008) identified that the young people with intellectual disability were mostly confident and experienced in their use of social media and were much more positive than many of the staff who worked with them.

Three of the papers described strategies to reduce risk. McClimens and Gordon (2009) and Kydland et al. (2012) prioritised safety concerns whilst helping people with intellectual disability to set up and use blogs or websites and found that, perhaps because of this initial support, no problems regarding safety were apparent. Kydland et al. (2012) found that some of the participants were concerned about their photographs being available to others and it was important to explain that they could limit access to their photographs through privacy settings and to agree rules about what photographs are acceptable to upload onto a photograph sharing application. Holmes and O'Loughlin (2014) established a group for people with intellectual disability which provided a psycho-educational approach towards internet safety.

Social Identity

Another strong theme that arose in eight of the papers was that of 'social identity'. Six of the studies showed that people with intellectual disability are provided with an opportunity to express social identity and voice opinions by use of online social networking (Holmes & O'Loughlin, 2014; Kydland et al., 2012; McClimens & Gordon, 2008, 2009; Seale 2001, 2007). The 'home pages' of people with Down Syndrome have been used as a means of speaking up about their lives, their feelings, wants and needs, with home page users often describing themselves by making reference to their friends, family and favourite activities (Seale, 2007; Seale & Pockney, 2002). A number of the papers discussed how online social networking provides people with an opportunity to present themselves in a manner of their choosing and project a preferred identity to the online world (Löfgren-Mårtenson, 2008; Seale & Pockney, 2002; McClimens & Gordon, 2008). Sometimes the identity that is projected may differ from the identity projected in the 'real world'. Indeed, some people with intellectual disability viewed the internet as a positive arena where they can be 'like

everyone else', presenting themselves without mentioning their label of intellectual disability and providing an opportunity to escape the stigma associated with intellectual disability (Löfgren-Mårtenson, 2008).

However this is not always the case and both Seale and Pockney (2002) and McClimens and Gordon (2008) found limited attempts were made by social media users to 'hide' an intellectual disability (e.g. Seale & Pockney (2002) refer to users detailing activities they have taken part in with disabled friends). In the study carried out by McClimens and Gordon (2008), all of the participants made some reference to their disability either by outright claim or by description of their daily routines and 'publicised' their intellectual disability despite the medium of the blog providing them with an opportunity to focus on other aspects of their lives.

Support

Six of the papers had findings linked to the support needed (from parents, carers, staff members or teachers) for people with intellectual disability to access social media (Holmes & O'Loughlin, 2014; Kydland et al. 2012; McClimens & Gordon, 2008, 2009; Seale, 2001, 2007). As a note of caution, the studies carried out by Kydland et al. (2012) and McClimens and Gordon (2008, 2009) described research projects where people with intellectual disability were chaperoned while learning new social media skills; therefore, the identified support needs may not reflect the issues that people experience when accessing social media independently.

Kydland et al. (2012) examined what support people with intellectual disability would require to use the website Flickr. They found that participants needed support with: logging in, uploading pictures, commenting on photos and searching. In terms of commenting on photos, this was a more complex issue than just the process of commenting itself and had more to do with knowing what kind of comments to write

(see the cyber-language and etiquette theme). McClimens and Gordon (2008, 2009) also found that participants had some difficulties with expressing themselves sufficiently to write content and needed support with literacy and some ICT skills. Kydland et al. (2012) found that support made an impact on outcomes. After an initial period of difficulty in engaging participants in Flickr, support (aiding confidence and technical competency) meant that gradually the participants were expressing themselves individually leading to greater engagement. The impact of effective support was also discussed by Holmes and O'Loughlin (2012) whose research participants were involved in a 'therapeutic group' which aimed to provide practical and emotional support for social media users. Participation in this group led to service users reporting that they were more confident problem solving when using the internet.

Seale (2001, 2007) also looked at support and identified that some of the 'home pages' in her study were written in the third person indicating that a parent or friend were helping with writing. Seale (2001, 2007) discusses how motivations for support and the level and type of support may vary, including a range from intensive one-to-one structured guidance to protective mediation to collaborative partnerships. There are potential conflicts of interest and possible vested interests if people with intellectual disability are being supported by family members and/or professionals to access or publish information on the internet. Seale (2007) raises this as an issue because the extent to which social media can be used by people with intellectual disability to speak up against oppression is likely to be influenced by the degree to which they are being supported in using the social media tool.

Relationships

The ability to make new friendships and maintain existing friendships online was a theme that arose in six of the papers (Holmes & O'Loughlin, 2014; Kydland et al., 2012; Löfgren-Mårtenson, 2008; McClimens & Gordon, 2008, 2009; Seale & Pockney, 2002).

Seale and Pockney (2002) found that of 20 participants, four identified having 'cyber-friends' and in a couple of cases this had led to friendships 'in real life'. Löfgren-Mårtenson (2008) found that when developing relationships, people with intellectual disability were sometimes given more freedom to choose and maintain friendships of their own choices online; sometimes participants had been able to contact people they already knew, but were unwilling to contact in real life and could plan and decide for themselves how to arrange meetings with friends, enabling a private life. The papers reported instances of relationship forming being a positive experience. Online relationships could supplement real life interactions (Holmes & O'Loughlin, 2014). Kydland et al. (2012) found some indication that Flickr may be helpful in reducing loneliness among people with mild to moderate intellectual disability. However, despite this evidence that suggests online relationship forming and maintaining can be beneficial and enjoyable for people with intellectual disability, the papers also provide evidence that it is not always straightforward. Holmes and O'Loughlin (2014) found that participants had experienced problems with understanding the word 'friend' in a sense that is used on Facebook. Even when people were apparently actively using social media, a number of these studies found that participants did not make new contacts or friends outside of the group working on the research project (Kydland et al. 2012; Löfgren-Mårtenson, 2008; McClimens & Gordon, 2008, 2009; Seale 2001, 2007; Seale & Pockney, 2002).

Happiness and Enjoyment

Six of the papers identified aspects of how using online social media was enjoyable and beneficial to personal happiness (Didden et al., 2009; Holmes & O'Loughlin, 2014; Keskinen et al., 2012; Kydland et al., 2012; Löfgren-Mårtenson, 2008; McClimens & Gordon, 2009). Papers were coded to be included within this category if they specifically referred to results related to happiness, fun or using the internet for reasons of enjoyment.

Didden et al. (2009) demonstrated that the internet was most commonly used for recreational and fun activities such as messaging with Microsoft Network (MSN), and sending and receiving emails. Young people with intellectual disability considered the internet to have given them many positive experiences and adventures (Kydland et al., 2012; Löfgren-Mårtenson, 2008) and felt that communicating with other people online was fun (Keskinen et al., 2012). As mentioned in the previous section on 'relationships', happiness and a possible reduction in loneliness (Kydland et al., 2012) was boosted by the number of online friends (Holmes & O'Loughlin, 2014, Kydland et al., 2012). Participants in Kydland et al.'s (2012) research stated that social functions such as creating a group for swapping photos were key for enjoyment and engagement in the activity.

Happiness and enjoyment were also gained by the increase in self-confidence and self-esteem as a result of learning new skills such as reading comprehension (Holmes & O'Loughlin 2014; Löfgren-Mårtenson, 2008; McClimens & Gordon, 2008, 2009). Self-esteem was also reported to have been increased through having an outlet to talk and voice opinions about activities, feelings, hobbies, wants and needs (Holmes & O'Loughlin, 2014; Kydland et al., 2012; McClimens & Gordon, 2009).

Social Media Usage

How widespread the use of social media by people with intellectual disability is and what kinds of social media people were using was also an important theme.

The most informative paper in this respect is Didden et al.'s (2009) study where almost all participants (students with intellectual disability, aged 12-19 in special education settings) owned mobile telephones and had access to the internet at home (97%). The most common uses for the internet were social (MSN (67%), playing online games (57%), emails (43%), putting information about oneself on the internet (27%), chatting on a website (24%) and using Skype (12%). Similarly, Löfgren-Mårtenson (2008) found that most of the study participants (young people in Sweden) had grown up with the internet and had learned by themselves or through siblings how to use computers and the Internet, and used them on a daily basis. Kydland et al.'s (2012) participants were frequent users of Facebook. However, Keskinen et al. (2012) found that only two out of five of their sample had used a computer to communicate with family and friends prior to their research. This could suggest that social media use may be more widespread amongst some groups of people with intellectual disability (i.e. younger people).

The follow up research carried out within the Kydland et al. (2012) and the McClimens and Gordon (2008, 2009) studies found that participants had a limited continuation of using the social media they used as part of the research process. For example, Kydland et al. (2012) found that only six out of 12 participants said that they would like to continue using Flickr after the end of the research project.

Communication and Literacy skills

Communication and literacy skills was a theme that arose within five of the papers (Holmes & O'Loughlin, 2014; Keskinen et al., 2012; Kydland et al., 2012, Löfgren-Mårtenson, 2008; McClimens & Gordon, 2008).

Literacy and communication difficulties were identified as a barrier for people with intellectual disability to freely access social media tools that they may wish to use. In a simplistic way, literacy problems in terms of reading and writing material on social media sites were identified as causing difficulties for participants in two of the studies (McClimens & Gordon, 2008; Kyland et al., 2012). However, the barriers are actually more complex, and cognitive, communication and literacy difficulties combine to cause problems with the ease of writing content, particularly when participants were not used to expressing themselves about aspects of their lives in writing (McClimens & Gordon, 2008). This can lead to misunderstandings and distress (Holmes & O'Loughlin, 2014). The material participants were able to put on to the blogs was often not in sufficient depth to initiate responses from 'others' (McClimens & Gordon, 2008).

Cyber-Language and Cyber-Etiquette

The theme of 'cyber-language and cyber-etiquette' emerged from five of the papers (Holmes & O'Loughlin, 2014; Kydland et al., 2012; Löfgren-Mårtenson, 2008; McClimens & Gordon, 2008, 2009).

Regular social media users become accustomed to the use of abbreviations and use of a 'cyber-language'. Some participants felt that 'cyber-language' has advantages for people with intellectual disability as they can 'get away' with not using correct spelling and grammar (Löfgren-Mårtenson, 2008). However, 'cyber-language' was also identified in the papers as a barrier to full and easy use of social media. For example, Kydland et al. (2012) and McClimens and Gordon (2008, 2009) identified difficulties with multiple meaning of words and one of the participants in the study by Holmes and O'Loughlin (2014) had difficulty understanding the word 'friend' in the sense that it is used in Facebook.

Difficulties with 'cyber etiquette' also caused problems for some participants. As previously mentioned, McClimens and Gordon (2008) identified a low level of online interaction with people from outside of the research group. One reason identified for this was that when developing a blog, there needs to be a complex combination of pictures and text to invite responses; this can sometimes only be achieved by experienced blog users and readers. Again, Keskinen et al. (2012) found that limitations in the participants' cyber-etiquette skills adversely affected their response to incoming communication; for example, participants sometimes carried on with their own story rather than responding to incoming messages. Holmes and O'Loughlin (2014) identified that all three of their participants in the paper had some problems with etiquette on the internet (e.g. revealing personal details publically and responding to 'group' invitations). Possibly due to a combination of these factors, Löfgren-Mårtenson (2008) found that most participants preferred email rather than 'cha't and suggest that this could be due to the impact of 'cyber-etiquette' where subtle codes of internet chat can be challenging whilst email can be conducted away from the pressure of 'live' instant chatting.

Accessibility

Three papers looked specifically at the final theme: accessibility and design in relation to the availability and appropriateness of equipment through which social media sites are accessed (Keskinen et al., 2012; Kyland et al., 2012; McClimen & Gordon, 2009).

Barriers were identified as being: the lack of appropriate facilities at home (McClimens & Gordon, 2009), the design of equipment (Keskinen et al., 2012), and the design of websites or apps (Kyland et al., 2012). Keskinen et al. (2012) found that whilst touch screens can be more accessible than computer mice or keyboards,

they were still impossible for people with motor impairments to use. It has been suggested that some social media tools can be more easily used by people with intellectual disability, such as photograph sharing applications which do not require high level literacy skills and have less emphasis on communicative interaction (Kyland et al., 2012) and customisable picture-based instant messaging communication systems (Keskinen et al., 2012). The study by Keskinen et al. (2012) examined symbol based systems that aim to increase accessibility. Participants felt that the symbols were good, clear and easy to learn. However, the number of pictures were also reported to be overwhelming, and a great deal of caregiver support was needed to use the system. Kydland et al. (2012) found that multiple ways of logging in and the process of adding photographs could, without support, make Flickr inaccessible to participants with intellectual disability.

Methodological Quality

While the findings presented provide an insight into the use of social media by people with intellectual disability, there are a number of methodological issues which need to be raised in relation to the studies included in the review. Almost all of the papers have very small samples. Some papers give no details of the sample size or demographics (McClimens & Gordon, 2008, 2009) and some papers give limited information on specific analysis (McClimens & Gordon, 2008, 2009) or methods. For example, Holmes and O'Loughlin (2014) present three vignettes. The paper says that "discussion of online networking has become common place within our clinical sessions" but no details are provided on how the vignettes were developed.

People with intellectual disability who have a particular interest in social media are clearly over-represented in the group of people who took part in the studies. Some of the papers only included participants who were already online (Holmes & O'Loughlin,

2014; Kydland, 2012; Seale 2001, 2007; Seale & Pockney, 2002). Other studies recruited participants who were likely to be social media users; Löfgren-Mårtenson (2008) for example used a snowballing technique for recruiting interview participants and so increased the likelihood that participants were only those interested in the research and social media.

Another methodological consideration is that some of the studies were projects looking at the experience of using social media and therefore do not represent a typical 'real life situation'. Some benefits may have been the result of taking part in research rather than the consequence of social media usage per se (Kydland et al., 2012; McClimens & Gordon 2008, 2009).

Finally, as previously mentioned, most of the participants across the ten included papers appeared to have relatively mild intellectual disability. It is likely that experience of using social media will be affected by severity of disability. For example, the women in Holmes and O'Loughlin's (2014) study appeared to be using Facebook independently. However this freedom and ability to use social media independently led to safeguarding concerns that, perhaps, would not have arisen for a person with greater support needs.

Discussion and Implications for the Future of Social Media Use for People with Intellectual Disability

The findings of this review suggest that opportunities exist for positive experiences for people with intellectual disability using social media and yet the barriers to regular use can be difficult to overcome. The studies indicated potential benefits of social media:

- increasing opportunities to make and maintain relationships

- providing another means to express a social identity, talk about lives and experiences and voice opinions
- increasing self-confidence and self-esteem through learning new skills
- providing enjoyable activities.

However, the barriers to successful social media use identified by the review are also complex, incorporating:

- safety and safeguarding concerns
- accessibility and availability of support
- potential misunderstandings of cyber etiquette
- the communication and literacy skills of people with intellectual disability
- the reluctance of people without intellectual disability to engage with a marginalised group.

The findings presented here support the findings of Parsons, Daniels, Porter and Robertson (2006) who found that the majority of ICT use by people with intellectual disability served as 'bonding social capital', maintaining pre-existing networks and relationships rather than enabling people to engage with the wider community and society. As introduced at the beginning of this paper, this kind of social capital can be negative when non-group members are excluded from having access to the same benefits as members (Steinfeld et al., 2008).

These findings corroborate the benefits of and barriers to the use of the internet by people with intellectual disability identified by other reviews and studies (Chadwick, Fullwood & Wesson, 2013; Chadwick, Wesson & Fullwood, 2013; Hoppestad, 2013; McKenzie, 2007). However, the focus of the research on social media has been on identifying and analysing barriers at the level of individuals, their family and paid

carers and social media sites. There is a lack of detailed exploration of the wider social, economic and political barriers to internet and social media use, and links to the social exclusion and marginalisation of people with intellectual disability.

There is conflicting evidence about the level of social media use amongst people with intellectual disability within the studies identified by the review. Three studies found high levels of internet access and use for social means (Didden et al., 2009; Kydland et al., 2012; Löfgren-Mårtenson, 2008). This contradicts research which has found lower levels of internet use between disabled and non-disabled people internationally (Guo, Bricout & Huang, 2005; Fox, 2011; National Telecommunications & Information Administration and Economic & Statistical Administration, 2013; Office for National Statistics, 2013). This could be due to the small unrepresentative samples of the studies included in the review, higher social media use by people with intellectual disability in different European countries or a result of participants being younger and part of a generation born since 1980 that has grown up with access to computers and the Internet and therefore more likely to use social media (often described as 'Digital Natives', 'Millennials', or the 'Net Generation') (Margaryan, Littlejohn & Vojt, 2011).

Other studies included in the review suggested lower social media use amongst people with intellectual disability and it is likely that many people with intellectual disability, in particular those with greater support needs, are not engaging in long term or continual social media usage. Where the research papers describe projects where a social media tool was introduced to people with intellectual disability, there were various degrees of success regarding how much use of that tool continued beyond the end of the project. Participants who wanted to continue were typically the

ones that had been the most active during the intervention period (Kydland et al. 2012).

Given that this review has highlighted potential advantages to using social media, it is important to consider further, how usage could be sustained. Holmes and O'Loughlin (2014) found that "although safer online environments for social networking have been created specifically for people with intellectual disability (specialfriends.com), some of our service users have discussed how they would prefer to access less specialised social networks"(p. 3). Therefore, it is important that the barriers to using social media are examined and carefully removed wherever possible. It is crucial that this is done with care as there is a risk that rather than increasing opportunities for people with intellectual disability to develop relationships and counter oppression instead (i) they may be placed 'in a passive role where they are recipients of technological expertise and protective guardianship as opposed to active advocates for the opposition of oppression' (Seale, 2007, p. 185), (ii) they may continue to be marginalised and silenced by people not responding to the information that they post online (McClimens & Gordon, 2008), (iii) they may be put at risk of abuse (Holmes & O'Loughlin, 2014).

Seale (2007) highlights the dilemma of the extent to which adults with intellectual disability are enabled to make their own choices about online safety issues. Family members or service providers may experience conflicts of interest when encouraging and supporting independence clashes with their parental or professional role to protect and safeguard people with intellectual disability. However, many people with intellectual disability use social media safely; the majority of people in the study carried out by Didden et al. (2008) did not experience cyber-bullying. In addition, people with intellectual disability may have different attitudes towards risk than

parents and professionals; Löfgren-Mårtenson (2008) points out that “Generally speaking, the young adults do not assess the risk of getting into trouble as seriously as they assess the risk of not having anything at all ever happen to them” (p. 133). However, it is important that people with intellectual disability are supported to use social media safely. Safety was a theme that arose in eight of the ten papers and must be taken seriously in particular for those people with fewer support needs who may be using social media independently. Some of the papers have touched upon ways in which safeguarding and participation can work harmoniously. Holmes and O’Loughlin (2014) reported that following a number of safeguarding concerns, a support group was formed within the Learning Disability Team to discuss any concerns and issues that people with intellectual disability were experiencing online. The group aimed to be psycho-educational and provided information about panic buttons, privacy settings, potential problems as well as assertiveness training and internet safety. People felt more confident about internet use at the end of the group. Kydland et al. (2012) showed people with intellectual disability how to use privacy settings and gave clear rules about what was acceptable to post online; however, they found it more difficult to do this for people with more severe disabilities. McClimens and Gordon (2009) prioritised internet safety by holding a training session which discussed the need to use pseudonyms, to withhold private information, not to use offensive language, and ensuring that people with intellectual disability were always under direct supervision whilst blogging. Apart from safety and safeguarding concerns another barrier to becoming full users of social media was that of accessibility. It is anticipated that on-going developments in this area will increase usage. The use of automated speech recognition for selection of symbols and categories, user interface navigation and activation of

commands will be advantageous for some people with intellectual disability, as will the use of different physical control devices (e.g. sensor technologies, machine vision) and a symbol based approach (Keskinen et al., 2012). However, Chadwick, Wesson and Fullwood (2013) point out that there is little evidence of ICT and internet designers acting on “numerous legislative imperatives and societal obligations to promote inclusion and full citizenship of people with intellectual disability (e.g., UNCRDP, 2006, Equality Act, 2010)” (p. 381) or recognising that the principle of universal design, “the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialised design” (p. 381), is applicable to people with intellectual disability.

Future Research

Social media and its benefits and concerns of usage is a fast moving area in terms of development, uptake by people with intellectual disability and their families, and safeguarding concerns. It is important that research keeps up to date with these changes as research soon becomes invalid as the context changes. As this review has demonstrated, it is also important for researchers to obtain the perspectives of people with intellectual disability as well as carers, parents and paid staff working with people with intellectual disability due to the often differing views and experiences.

The review demonstrates that there is a lack of clear research evidence about whether a ‘digital divide’ exists whereby people with intellectual disability have unequal access to social media compared to people without intellectual disability, and whether and how access and usage may differ amongst people with intellectual disability. It would be useful if future large-scale surveys comparing internet and

social media use by disabled and non-disabled people differentiate between disabled people with physical and intellectual impairments so that such information could be gathered.

The research papers in this review have, as a whole, been methodologically weak with small samples. Future research needs to use more robust methods. There is also a need to develop clear theoretical models. The theoretical models referred to in papers relating to social capital (McClimens & Gordon, 2008, 2009), the social model of disability (Seale, 2007; McClimens & Gordon, 2008, 2009) and interdependence and autonomy (Seale, 2007) are varied and have not been developed enough to provide a clear theoretical framework.

Conclusion

Social media use is becoming a part of daily life for increasing numbers of people. This review has demonstrated that people with intellectual disability are gaining positive experiences from using social media in terms of nurturing friendships, development of social identity and self-esteem and for enjoyment. The review has also revealed barriers to people with intellectual disability successfully accessing social media: safety and safeguarding concerns, accessibility and availability of support, potential difficulties with cyber-language and cyber- etiquette and communication and literacy skills. This review has highlighted the lack of methodologically robust research and theoretical frameworks in this area.

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Figure 1: PRISMA FLOW DIAGRAM

Table 1: Details of studies included in the review

Authors	Social media tool	Participants	Key Findings
Didden, R. et al (2009)	Social networking	114 students aged 12-19 attending a school for special education students in the Netherlands. Participants had an IQ range of 52-118.	<p>Almost all had access to the internet at home (97%).</p> <p>Most used the internet for MSN (67%), playing online games (57%), emails (43%), putting information about oneself on the internet (27%), chatting on a website (24%) and using Skype (12%).</p> <p>5-12% were victimized at least once a week. Most students were not involved in bullying via the internet (90%) and via cellphone (86%).</p>
Holmes, K. M., and O'Loughlin, N. (2014)	Social networking site - Facebook	Three women in the UK with intellectual disability aged 25-30. Two women were referred to as having "a diagnosis of mild learning disability" and one as having a "diagnosis of a learning disability".	<p>Positive experiences: being able to keep in touch with people and increase social circle. Negative experiences: concern with regard to safety (being placed in potentially risky and vulnerable situations, cyber bullying, sexual and financial exploitation).</p> <p>A group was formed to address these online experiences and provide support. At the end of the group, people were more confident about online use.</p>
Keskinen, T, Heimonen, T,	Picture-based	Nine men in Finland aged 14-37. Severity of disability was rated by researchers. Two were rated 'low', 5	Only 2/5 already used a computer to communicate with family and friends.

<p>Turunen, M, Rajaniemi, J and Kauppinen, S. (2012)</p>	<p>communication platform – SymbolCh at</p>	<p>were rated ‘moderate’, one rated ‘high’ and one had no cognitive impairment.</p>	<p>Symbols were clear and easy to learn and it was easy to select them by touch. Message duration and length varied due to discussion topic, motivation and alertness, ease of formulating message content, knowledge about what symbols meant, finding symbols. Key development issues relate to application functionality (e.g. finding symbols) and communication, interaction and cognitive abilities.</p>
<p>Kydland, F, Molka-Danielsen, J and Balandin, S. (2012)</p>	<p>Flickr</p>	<p>12 people in Norway with intellectual disability (6 men, 6 women, aged 20-56). Participants were described as having “intellectual disability”. They were employed at a rehabilitation company; all have previous experience with computers, had access to and able to use their own computers and were able to give consent.</p>	<p>Participants stated that social functions such as creating a group for swapping photos were key for enjoyment and engagement in the activity. Almost all stated that they had a positive experience with Flickr. The extent to which the participants used Flickr varied. Technical challenges included logging on and searching. Also some difficulty explaining concepts of privacy and privacy settings. Six of the participants said that they would like to continue using Flickr. Participants frequently used Facebook and felt that this had more functions and was more fun.</p>

			Study showed some indication that Flickr may be helpful in reducing loneliness. However, none made new friends outside the group.
Löfgren-Mårtenson, L. (2008)	Social networking site - LunarStorm	Ten young people in Sweden, most of whom had mild intellectual disability - aged 18-31 (6 men, 2 women) and 12 staff members (10 men, 2 women).	People with intellectual disability used cyberspace as other teenagers and young adults do. They had several contacts online with people they already knew and new acquaintances. The website provided space for a private life beyond the surrounding world's control and a chance to contact potential partners but it was still unusual to meet a partner in real life. Although conscious about risks involved some of the young women behaved contrary to how they said they would. Participants were highly motivated to learn about cyberspace norms because (a) their desire for social contacts (primarily boyfriends and girlfriends), and (b) not being automatically classified as a person with intellectual disability. Participants felt that cyber-language was advantageous for people who have difficulties with reading and writing. Most preferred email.

			<p>There were discrepancies between staff members' and young people's views about the internet with staff worrying about safety. A few staff members pointed out positive aspects of more social contacts and practicing communication and spelling.</p>
<p>McClimens, A and Gordon, F. (2009)</p>	<p>Blog</p>	<p>Group of adults in the UK with intellectual disability and varying levels of literacy and keyboard skills.</p>	<p>Blogging was within the control of those using it and allowed self-expression. All felt that they had learned things about the process of blogging and themselves. There was trust and mutual congratulation within the group. However other people showed no interest in the blogs.</p> <p>The lack of facilities at home could prevent the continuation of blogging. Participants needed support with logging on, spelling and word processing.</p>
<p>McClimens, A and Gordon, F. (2008)</p>	<p>Blog</p>	<p>People with intellectual disability in the UK</p>	<p>Encountered literacy problems (not just in terms of reading/writing but ease of writing when not used to doing so). The published blogs suggest paucity of lived experience but it was unclear how much was actual and how much determined by the medium.</p> <p>No attempts were made to 'hide' from their intellectual</p>

			<p>disability status.</p> <p>The participants were able to enter blogosphere...albeit with limited success.</p> <p>Initial concerns around maintaining online safety were unfounded (perhaps aided by the protocols put in place).</p>
Seale , J.K. (2001)	Home pages	<p>Personal Home Pages (PHPs) of 20 people with Down Syndrome with an average age of 18.</p> <p>11 were men. 14 were American, 3 British, 2 Japanese and 1 Australian.</p>	<p>PHPs contained information on 3 main themes: Personal, Family and Down Syndrome and Disability.</p> <p>Computers and the internet featured heavily in the Personal subthemes.</p> <p>Analysis of language showed differences in 'voice' used to present the information. 7 PHPs were written in the first person, 8 were written in the third person and 5 were mixed. The language that PHP users used to describe themselves revealed differences in how they viewed themselves.</p>
Seale, J.K. and Pockney, R. (2002)	Home pages	<p>16 Personal Home Pages of adults with Down Syndrome from the Seale 2001 sample who referred to friendships.</p>	<p>Found that people with DS used home pages to attempt to present an image of themselves as someone who is capable of having friends. Guest book messages indicated readers of the home pages</p>

			responded to attempts at friendship.
Seale, J.K. (2007)	Home pages	15 home pages from the Seale 2001 sample that were still available for analysis.	Many of the authors of the PHPs were supported in their online publishing activities; in the majority of cases by family members. Often the homepage was part of a bigger family website. Questions were raised about the validity of online activities as vehicles for self-advocacy and the power relationships that such activities expose.

Table 2: Concept Matrix Identifying Main Themes

Article	Theme								
	Accessibility / Design	Social identity	Happiness & enjoyment	Communication and literacy skills	Safety and Safeguarding	Cyber-language, cyber-etiquette	Relationships	Social media usage	Support
Didden, R et al (2009)			X		X			X	
Holmes, K and O'Loughlin, N (2014)		X	X	X	X	X	X		X
Keskinen, T et al (2012)	X		X	X					
Kydland, F, Molka-Danielsen, J and Balandin, S (2012)	X	X	X	X	X	X	X	X	X
Löfgren-Mårtenson, L (2008)		X	X	X	X	X	X	X	
McClimens, A and Gordon, F (2008)		X		X	X	X	X	X	X
McClimens, A and Gordon, F (2009)	X	X	X		X	X	X	X	X
Seale, J (2001)		X			X				X
Seale, J and Pockney, R (2002)		X					X		
Seale, J (2007)		X			X				X
Totals:	3	8	6	5	8	5	6	5	6