# A Critical Review of Literature on Social Media and Developmental Communication Disability: Implications for Future Social Media and Generative AI Research

Bronwyn Hemsley[1] · Fiona Given[1] · Barbara Almond[1] · Jenna Cooper[1] · Rebecca Smith[1,2] · Kirsty Young[1] · Evana Wright[1]

## Abstract

**Purpose of Review** The widespread use of social media and recent development and use of generative artificial intelligence (GenAI) has implications for the advancement of inclusive communication technologies to benefit people with developmental communication disability. This paper synthesises and critiques recent research on social media use in populations with developmental communication disability, discusses the intersection of social media and GenAI that could impact this population, and provides directions for future research.

**Recent Findings** There is encouraging growth in the use of innovative methods to gather the views of people with developmental communication disability on their use of social media, advancing understanding of the risks they face and how they and their supporters manage these risks. However, there continues an underutilization of social media data published by and with people with developmental communication disability and a lack of co-design. Moving beyond patterns and purposes of use, future inclusive and co-designed research with this population should (a) include social media data, whether independently or co-produced with supporters; (b) explore the under-researched legal, ethical, and safety issues; (c) measure the outcomes and impact of social media publication in relation to the user or user group's emancipation, education, and enablement; and (d) consider the impact of GenAI on social media use for this group.

**Summary** Continued attention to the safe and enjoyable use of social media for all those who wish to use it, and foundational research on the uptake and use of GenAI, will be important to understand and support the advanced communication technology support needs of people with developmental communication disability. To inform future advances in both social media and GenAI for populations with developmental communication disability, future research directions are proposed.

**Keywords** Social media · Developmental communication disability · AI · Generative AI · GenAI · Identity · Self-determination · Technology

## Introduction

### Social Media and Developmental Communication Disability

For approximately 60% of the world's population [1], social media is an integral part of daily life that is used for countless diverse purposes: enabling people to keep in touch,

✉ Bronwyn Hemsley
  Bronwyn.Hemsley@uts.edu.au

[1] The University of Technology Sydney, Ultimo, Australia

[2] Western Sydney University, Sydney, Australia

form new relationships, maintain and enrich friendships, exchange information, obtain education and employment, and solve problems [2]. Likewise, social media is used by people with developmental communication disability (i.e., associated with developmental disorders affecting communication, including cerebral palsy, intellectual disability, and autism) for social connectedness, self-advocacy, making new friends, keeping in touch, and obtaining information [3]. These purposes of using social media are particularly important in populations with developmental communication disability, who are at risk of social isolation and lacking access to information [4].

In 2019, Sweet and colleagues [5] reviewed 59 articles on the use of social media by people with disability and

identified six key content themes related to using social media, with the strongest being 'community' (community-building around friendships, information, social support, identity, and advocacy). The authors concluded that social media supported access to new social opportunities, collaboration, advocacy, and support; and that information exchange on social media fosters important learning skills. However, research also shows that populations with developmental communication disability are often excluded from social media participation [6] for many reasons; including restrictions being placed upon them by gatekeepers, lack of access to the internet or the required computer devices such as computers and smart phones, lack of knowledge or skills and informed supporters for learning social media, and negative experiences online [2, 3, 7].

And yet, despite gaps in equitable access to social media, people with disability are over-represented in relation to problems with social media safety, cyberbullying, and the negative impacts of social media on mental health [8]. For example, research on the use of social media in young people has shown that people with disability, along with other minority groups, experience higher rates of bullying and abuse online compared to the general population [8], and greater impacts of social media addiction and harms affecting mental health [3, 9, 10]. Accordingly, there is growth in research on teaching people with developmental communication disability to use social media safely, including by peer- and older-age mentors and in providing supports and mentoring for safe and enjoyable use with positive impacts and few adverse outcomes reported [4, 11, 12].

In 2017, Hemsley and colleagues [13] synthesised the literature to identify barriers and facilitators to social media and propose an agenda for innovative research prioritising six main areas of inquiry: (i) legal issues: publicity/privacy in social media use; (ii) legal issues: social media publishing; (iii) ethical issues: conduct of social media research; (iv) ethical issues: autonomy and personal control; (v) social media skills; and (vi) safety issues. Providing 37 examples of future research questions across these six categories, the authors urged researchers in the field towards greater innovation, building on the foundations of social media research in disability, to (i) 'implement a wider range of social media data collection and analysis methods that make use of social media data, and attend to diverse and multiple social media platforms' (p. 20) and (ii) focus on safety and cyber-resilience across social media platforms; to develop interventions that help to prevent harmful social media incidents and reduce gatekeeping activities used to prevent people from 'accessing social media in the same way as their peers without disabilities' (p.20). Given that 5 years have passed since publication of the most recent review, we aim to review research since then on the use of social media by people with developmental communication disability to determine how far the research agenda proposed in 2017 [13] has been fulfilled and to further inform a future inclusive research agenda.

## Materials and Methods

### Search for Social Media Literature for Screening

Multiple methods were used to locate relevant literature for the narrative review. In June 2023, a targeted and purposive search of the Scopus scientific database was conducted by the first author (a speech-language pathologist) and the second author (an adult with developmental communication disability associated with cerebral palsy, who is a trained lawyer and person who uses augmentative and alternative communication (AAC)) using the following search terms in various combinations (social media, Facebook, Twitter, Instagram, communication disability, developmental disability, cerebral palsy, intellectual disability, and autism). This was done to locate original research of any design published in the last 5 years since publication of the most recent review in 2017 [13] and relating to social media and populations with developmental communication disability. Scopus was selected as a suitably inclusive scientific database likely to identify relevant studies reporting on original, peer-reviewed research. In addition to the Scopus search, a purposive forward and backward citation search of Hemsley et al. [13] was also conducted to locate studies meeting the inclusion criteria.

### Screening

The titles of all potentially relevant articles located in Scopus and by the citation search ($n = 820$), containing no duplicates, were screened for inclusion by the first, second, and third authors arriving at consensus on the exclusion of studies not relating to social media, not being original research in English available in full text, or not specifically documenting the inclusion of populations with developmental communication disability. From these 820 studies, 81 potentially relevant studies were retrieved for full text review. On review of full texts, 40 of these studies progressed to data extraction, which involved creating an Excel spreadsheet of study populations, social media platform, and aims and methods for further consideration. Upon examination of the extracted data, 21 of these studies did not yield any results relating to the use of social media in populations with developmental communication disability and were excluded. The remaining 19 studies were included in the review, and the Mixed Methods Appraisal Tool (MMAT) [14] was used to appraise the quality of the studies; all of which were of a suitable design

to answer their research questions with data analysed according to the design and interpreted appropriately.

## Content Analysis

The full text files of the 19 studies were imported into NVivo for content coding by the first author, in consultation with the second author, to determine any categories of meaning in the results across studies [15]. This involved reading and re-reading the texts and applying NVivo codes to any identified units of meaning in the results of each study. These open codes were then arranged into categories, and themes identified that connected the categories, to explain the findings across the studies. In order to map how well the studies had met the research agenda proposed in 2017 [13] and identify persistent gaps in the research, the main focus of each study was also identified.

## Results

### Characteristics of the Social Media Studies

The characteristics of the 19 studies included in the review of social media and developmental communication disability are outlined in Table 1.

### Dates and Countries of Publication

Dates of publication were relatively evenly spaced over the years since 2017. Studies were from Australia ($n = 5$), Sweden ($n = 5$), United Kingdom ($n = 3$), United States of America ($n = 2$), Germany ($n = 1$), Israel ($n = 1$). Korea ($n = 1$), and South Africa ($n = 1$).

### Methods

Of the 19 included studies, the majority ($n = 11$, 58%) were qualitative, using in-depth interviews online or in person. Four were mixed-methods studies using surveys, scales, observations, and interviews; and four were quantitative studies using survey [28], single case multiple baseline design [13], or pre-experimental designs [12, 26]. Two studies made use of instant message chat for some participants with intellectual disability [22, 23] and one online focus group used a text-based forum on Wikispaces [21]. Only three studies (15.7%) collected the participants' social media data: (i) Hemsley et al. [13] harvested Twitter data for quantitative network analysis and to triangulate with in-depth interviews; (ii) Kim et al. [27] had participants with ID show their accounts on social media to the researcher during in-person interviews about their use of social media; and (iii) in a mixed-methods study involving observations

and interviews [18], researchers captured 269 photographs of social media data on the screens of participants (av. 18 per participant) for researchers to use 'as memory aids and picture-based support during follow-up interviews and when transcribing field notes' (p. 128).

### Populations and Social Media Platforms

The 19 studies included a total of 1116 participants with disability and 982 non-disabled participants, being 148 parents, legal guardians, support workers, and managers of people with disability [11, 16, 17, 20, 25] and 828 adolescents without disability [17]. Four studies (21%) did not include any participants with disability and reported the views only of supporters (e.g., parents, direct support workers, or managers at centres) [16, 17, 20, 25]. None of the studies reviewed specified co-authorship was with people with developmental communication disability or that the studies were co-designed.

Of the 17 studies reporting on the age of the target population of people with disability, 10 related to adults, seven related to both adolescents and young adults, and none related only to children. Almost all the studies were small in scale ($n = 16$, 84%) with an average of 13.6 participants (range 3–30). Three larger scale studies involved a survey of 94 parents and legal guardians of adolescents with ID on their use of the internet [17], interviews with 571 adults with ID on their use of the internet during COVID-19 [2], and an anonymous survey of 370 adults with ID who had attended a healthcare facility in New York on their use of technology and social media [28].

### The Main Aims of the Studies

Overall, the 19 studies focused on five main aims, being to: (a) understand the views and perspectives of participants with disability on social media specifically or the internet more broadly with questions on social media; (b) understand the views and experiences of parents/legal guardians, support workers, or managers on the use of social media by people with developmental communication disability (e.g., associated with cerebral palsy, intellectual disability, autism, and genetic syndromes); (c) identify barriers to and supports for the use of social media in this group; (d) determine the outcomes of any interventions aimed at improving social media skills in people with developmental communication disability; and (e) identify the outcomes or impacts of social media use on this group, including how social media influences relationships, social connectedness or inclusion, identity, or disability self- or community-advocacy online. Most studies related to any social media platform, with participants often reporting use of multiple platforms, and one study focused specifically on teaching adults who use

**Table 1** Characteristics of studies included in the review relating to social media and developmental communication disability

| First author (year) | Population | Participants | Main aim(s) | Method(s) | Analysis | Further contextual details |
|---|---|---|---|---|---|---|
| Agren (2020) [17] | Youth with ID | 94 parents/legal guardians (mean age 48 years) of adolescents with ID (aged 13–20 years) 828 parents/legal guardians of adolescents without disability) | To investigate opportunities and risks of internet use as viewed by the parents/legal guardians and compare this with a national reference group | Quantitative Cross-sectional survey with group comparison | SPSS 25 for statistical analysis | |
| Agren (2023) [18] | Youth with ID | 15 children and young people with mild or moderate ID (aged 13–24 years) | To explore environmental opportunities and challenges when performing internet activities and how internet use influences social and community participation | Qualitative Observations (including of participants in their school setting, internet use, and photos of screens) and follow-up interviews | Thematic analysis | |
| Bosse (2020) [19] | Children and youth with complex communication needs | 24 students with CCN (aged 10–23 years) | Explore patterns of internet and social media use; facilitators and barriers; comparison to similar populations in other countries | Quantitative Survey (written hard copy) based on a survey used in other countries | Descriptive statistics | 18 were internet users and 6 were non-users 5% had no internet device 58% were online every day Reading skills mediated internet use |
| Buchholz (2020) [20] | People with cognitive disabilities I/DD (schools, work settings, and accommodation) | 21 support persons (10 family, 7 staff, and 4 family and staff) (aged 28–61 years) | Explore support person's views on remote communication and factors enabling self-determination and participation | Qualitative Focus groups (5) | Thematic analysis of written focus group data | Supporters had supported people with developmental or acquired disabilities and communication/cognitive impairments |
| Caron (2017) [21] | Youth who use AAC | 7 adolescents with cerebral palsy (aged 14–21 years) | Investigate experiences of using social media (advantages, disadvantages, barriers, and supports) to inform service providers and develop future interventions | Qualitative Online discussion group forum on Wikispace | Thematic analysis | All participants used high technology AAC (speech generating devices) |
| Caton (2022) [2] | Adults with mild to moderate ID | 571 adults with mild to moderate ID (aged 16–55+years) capable of giving consent and participating in an interview | To explore how people with ID used the internet across the UK during the COVID-19 pandemic | Mixed methods. Interviews online (Zoom, Teams, WhatsApp, Messenger, and Face-Time) or telephone call | Quantitative analysis in SPSS26 (Fisher's exact test, Chi-square, two-sided; relative risk calculation) Thematic analysis | Study was conducted April–May 2021 89.8% of participants used internet at home; 60.6% used internet for social media purposes |

**Table 1** (continued)

| First author (year) | Population | Participants | Main aim(s) | Method(s) | Analysis | Further contextual details |
|---|---|---|---|---|---|---|
| Chadwick (2018) [22] | Adults with ID | 11 adults with ID (aged 20–43 years) | To discover how experiences online and using social media related to their sense of self, social relationships, and identity | Qualitative. Interviews (face-to-face or online on Facebook Messenger by instant message) | Thematic network analysis | All participants used the Internet and Facebook |
| Chadwick (2022) [23] | Adults with ID | 13 adults with mild to moderate ID (aged 20–50 years) | Determine the views of adults with ID on their experiences and impacts of content, contact, and conduct risks online and in social media | Qualitative. Interviews (face-to-face or online on Facebook Messenger by instant message) | Thematic network analysis | 11 of the adults used social media daily (8) or weekly (3); 2 never used social media |
| Dada (2022) [24] | Adults who use AAC | 10 adults who had attended an AAC camp (aged 19–34 years) | To understand friendship experiences | Qualitative Interviews | Thematic analysis | Technology mediates friendship experiences |
| Darragh (2017) [7] | Adults with ID | 30 adults with ID (aged 20–60+) | To explore if people with ID access internet based social media and if they use it to form relationships that express their sexuality | Qualitative. Interviews (in-depth, conversational style) | Thematic analysis | Some organisations involved in recruitment censored participants from being asked some of the questions about sexual feelings or expression |
| Engwall (2022) [25] | Adults with ID | 17 supporters (11 support workers at day centres, 2 other support workers, 4 directors) (ages not reported) | To analyse the digital process mobilised by staff in the wake of COVID-19 restrictions and centre closures. What were the processes and how were they received, the challenges, and future prospects | Qualitative. Interviews | Content analysis | The two additional support workers interviewed (not at the centre) were selected as having a positive attitude towards the digital project and effectively supporting service users in the digital process |
| Grace (2019) [26] | Youth who use AAC | 4 young people who used AAC (aged 13–18 years); 2 mentors who used AAC (aged over 40+years) | To examine the potential contributions of cross-age peer e-mentoring to enhance online conversations for young people who use AAC | Pre-experimental design Single group pre-test post-test design; SEAS-PCS rating scale; at four time points (6 months before intervention, 8 weeks into the intervention, at 16 weeks at the end of the intervention, and 6 weeks after the intervention) | Descriptive analysis of patterns of ratings on the SEAS-PCS | |

**Table 1** (continued)

| First author (year) | Population | Participants | Main aim(s) | Method(s) | Analysis | Further contextual details |
|---|---|---|---|---|---|---|
| Grace (2023) [11] | Youth who use AAC | 4 young people who use AAC (mentees aged 13–18), their parents (number and ages not reported), and 2 mentors (aged 40+ years) | To determine the effect and perception of a cross-age peer e-mentoring intervention on goals for online conversation | Mixed-methods. Survey goal attainment measure and interviews | SPSS 23 used for statistical analysis. Pre- and post-COPM ratings were analysed using paired t-test. Goal Attainment Scale levels were expressed as a T-score. Qualitative descriptive analysis of goals and interventions, content thematic analysis of interviews | |
| Hemsley (2018) [4] | Adults who use AAC | 3 adults who used AAC and Twitter (aged 35–50 years) | To determine the impact of teaching people who use AAC how to use Twitter | Mixed methods. Single case multiple baseline experimental design Analysis of social media content and network data | Descriptive statistics on Twitter follower count, frequency of tweeting, tweet content, and development of social networks. KH Coder software analysis and visualisation, and Gephi software analysis of the Twitter network | Restricted to Twitter; two participants showed improvement in Twitter skills and strategies |
| Kim (2021) [27] | Adults with ID | 20 adults with ID (aged 20–49 years) living in Korea | To understand the experiences of social media use among people with ID in Korea, including benefits and challenges from the user perspective | Qualitative Interviews in person | Thematic analysis | |
| Patrick (2020) [28] | Adults with I/DD | 370 adults with I/DD attending a healthcare facility in New York (Sept–Dec 2016) (aged 18 to 70+years) | To explore the prevalence of technology and social media use and barriers to use for adult patients with I/DD | Quantitative. Cross-sectional accessible survey on a touch-screen tablet device, using software that enabled use of images and audio for each question to enhance independent completion | SPSS 22 was used. Responses according to age strata were analysed using chi-square test. Descriptive statistics (frequency of categorical responses) and lists of open-ended responses were categorised | Less than half of the participants used a device (tablet, smartphone, desktop, laptop, or other). Most (86.8%) did not use social media. Those who did reported using Facebook and Instagram |

**Table 1** (continued)

| First author (year) | Population | Participants | Main aim(s) | Method(s) | Analysis | Further contextual details |
|---|---|---|---|---|---|---|
| Raghavendra (2018) [12] | Youth with I/DD | 9 young people (aged 14–19 years) with ID (4); Williams syndrome (1); muscular dystrophy (1); autism (1); learning difficulties and dyslexia (1); Landau-Kleffner syndrome (1) | To investigate the effectiveness of teaching social media use to youth with disabilities living in rural South Australia and whether it increased their social networks | Mixed methods. Pre-and post-intervention findings; interviews after the intervention for experiences and views on outcomes | Quantitative results analysed using statistical analysis, paired *t*-tests, Wilcoxon signed rank test, T-scores; Qualitative data analysed in NVIVO, inductive thematic analysis | |
| Ramsten (2020) [29] | Adults with ID | 11 adults with ID (aged 22–31 years) | To describe the use of ICT from the perspective of young adults with mild-to-moderate ID in a municipal social care context | Qualitative. Interviews | Thematic analysis | Inclusion criteria specified this age range; and the ability to make one's own decisions about informed consent; using ICT in daily life; being able to read; and mild-moderate ID |
| Shpigelman (2017) [16] | Adults with ID | 16 participants without ID [8 relatives (parent or sibling) of 8 adults with ID; 8 direct support workers (of 12 people with ID)]. Average age of participants was 36.1 years | To understand and describe the point of view of family members and direct support workers on the use of Facebook by people with ID, to gain a better understanding of how they perceive the social capital benefits of people with ID using Facebook | Qualitative. Interviews. Phenomenology, face-to-face interviews | Thematic analysis | It was reported that of the 20 individuals with ID, 5 had other developmental disabilities (CP, autism, and vision impairment). Also, 14 of the individuals with ID had a personal computer and internet connection |

AAC to use Twitter [4]. There were no studies focusing on the content published on or use of Instagram, TikTok, or YouTube specifically. One study [7] focused on the views of adults with ID on their use of the online social media for sexual expression. The authors reported that despite the interview guide being ethically approved, one gatekeeping disability organisation restricted the questions that could be asked of the adults with ID (and capable of giving informed consent) about their social media use and removed some as the questions deemed '"too personal" as they pertained to asking about participant's sexual feelings" (n.p).

Since 2017, there has been encouraging growth in the representation of the views and experiences of people with developmental communication disability, reflected also in the concordant views of their supporters. When mapped onto the six suggested priority areas for future social media research [13] (see Table 2), it is evident that the research reviewed has advanced knowledge primarily in relation to the domains of 'social media skills' and 'safety issues', with some findings contributing important insights to the domains of 'ethical issues: autonomy and personal control' and 'Legal issues: publicity/privacy in social media use'.

## Content Thematic Analysis

### The Upside: Purposes, Drivers, and Benefits of Social Media Use

Across participant groups, the studies identified a wide range of benefits of people with developmental communication disability using social media.

**Fun, Entertainment, and Engaging with Interests** Social media use benefits included social media being fun, engaging, and entertaining (e.g., [2, 21, 29]). Participants reported using social media for amusement and as a solitary leisure pastime, using social media to engage in topics of interest (e.g., pets, sport, or food), to avoid feeling lonely, or 'combat social isolation through creating ample opportunities for social inclusion' [27] (p. 412). Social media provided 'the opportunity to follow celebrities or idols or to join a group with a specific interest, such as pets' [29] (p. 298). The entertainment value also related to posts being refreshed regularly 'because they change everyday because people add new posts' [21] (p. 35). People with communication disability reported using social media to play games 'all the time' [21] (p. 35) and looking through pictures and videos was highly valued. Parents also reported their sons or daughters feeling good through responses gained when sharing posts on Facebook. As one mother of an adult with ID reported 'I think it [Facebook] is fantastic. He knows a lot of people who share the same interests, like football, and this is amazing' [16] (p. 410).

**Identity, Self-assurance, and Pride** Authors reported participants with disability gaining more confidence and caring 'less about what other people thought about me after using Facebook' [27] (p. 415) 'just by the fact that someone knows about me [through Facebook] without even meeting me [makes me] a little proud' [27] (p. 414). Grace et al. [11] also reported a mentor describing use of social media by the person with disability as 'it was really worthwhile and I think there was a real sense of achievement once she'd done it' (p. 10). Some participants enjoyed a feeling of acknowledgement [27], receiving many 'likes', getting compliments, feeling like a celebrity, and an associated increased confidence and pride [16]. Autonomy in the expression of disability identity, and disability pride, also appeared across several studies, in the sense that people with ID posting about their daily lives could choose whether to acknowledge their disability [24] in the context of the post and able to 'exercise self-determination in letting others know of their disabilities on the internet' [27] (p. 416). Chadwick and Fullwood [22] noted that 'Accounts also incorporated the relational nature of the online self, that is, identity was defined by oneself and by inter-relationships and interactions with others'. (p. 57). This was supported by [27] who found that 'flexible disability identity' (p. 416) was supported by the finding that 'participants had the autonomy to reveal or hide their disabilities … they integrated how they feel with how they present themselves' (p. 416). In the same study, people with disability shared their stories on social media to 'show people that I am here' (p. 419) and one reported feeling 'pride in taking part in supporting the rights of people with disabilities' (p. 414).

**Making Contact and Keeping in Touch** Across the studies, findings reflected that social media usage increased the number of communication partners for the person with communication disability and facilitated social inclusion by easing social engagement [26, 29]. People with disability appreciated the increased number of people contacted through social media, as one adult with cerebral palsy stated 'I also like that if I send a message it can go to a lot of people not just one' [21] (p. 35). Studies commonly reported that social media helped to make social interactions easier, enabling the person to keep in touch with others [2, 7, 11, 12, 21, 24, 29], meet more people (e.g., unknown people with similar interests) [7, 29], and strengthen connections to enrich friendships [24, 29]. While one study [12] showed that there was not a significant increase in communication partners after a social media training intervention, there was nonetheless an overall increase in the mean number of online communication partners and an increased social connectedness for participants with I/DD. A parent of a woman with ID reported 'She manages to keep in touch with friends who don't live with her, which is another bonus' [16] (p. 410). Keeping in

**Table 2** Mapping of research findings according to suggested priorities for future research

| Key focus area suggested in a recent review [13] | Agren (2020) | Agren (2023) | Bosse (2020) | Buchholz (2020) | Caron (2017) | Caton (2022) | Chadwick (2018) | Chadwick (2022) | Dada (2022) | Darragh (2017) | Engwal (2022) | Grace (2019) | Grace (2023) | Hemsley (2018) | Kim (2021) | Patrick (2020) | Raghavendra (2018) | Ramsten (2020) | Shpigelman (2017) |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Legal: Publicity/privacy in social media use | | | X | | | X | | X | | | | | | X | | | X | | X |
| Legal: Social media publishing | X | | | | | | | | | | | | | | | | | | |
| Ethical: Conduct of social media AAC research | | | | | | | | | | X | | | | | | | | | |
| Ethical: Autonomy and personal control | | X | | X | | | X | X | X | X | | X | | X | X | | | | X |
| Social media skills | | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X |
| Safety issues | X | X | | X | | | X | X | X | X | | X | X | X | X | | X | | X |

touch was a particularly important benefit [2, 7, 12, 21, 24], as one adult with ID described liking social media 'because I can talk to and see pictures of friends and family who live far away, who I cannot see [in person] all the time' [21] (p. 35).

**Maintaining and Enriching Friendships** The 'keeping in touch' category was related also to the outcome of this contact being to enable, maintain, and enrich friendship connections [24]. Several studies reported that the use of social media not only helped people to make new contacts but also to develop and strengthen friendships online and in person (e.g., [12, 21, 24]). Being able to keep in touch frequently was also important, as one participant reported: 'I do that as soon as I wake up – I check Facebook then when I sit and eat breakfast, I read the news, check Facebook again, at Instagram. Later, when I get to work, I check Facebook again [to see] if someone has made an update' [29] (p. 297). Chadwick and Fullwood [22] reported that being connected online in social networks supported relatedness and sharing and 'facilitated maintenance of existing social capital' (p. 57). Ramsten et al. [29] also reported that social media 'attracted their attention throughout the day. A common use … was to chat and stay updated with friends and relatives' [29] (p. 297).

**The Downside: Risks, Harms, and Risk Management in Social Media Use**

**Overuse, Compulsion, and Addiction** Notwithstanding several reports in the studies of the beneficial aspects of using social media, and being an important part of daily life, these aspects also contributed to some of the negative outcomes of that use. Addiction to social media appeared in three studies, with Kim and Qian [27] reporting that 'participants experienced risks and addiction' and were 'aware of their unhealthy lifestyles related to SNS [social networking site] addiction' (p. 418), and one participant felt addicted in using social media 10 h per day and another reported not getting sufficient sleep due to consistently reading Facebook. Chadwick [23] reported that 'overuse' of the internet and social media led to 'reduced occupational, social and developmental opportunities' (n.p) for six participants with ID; and Shpigelman et al. [16] noted that parents and legal guardians reported a family member or client with disability had 'limited conceptual and social skills', which could lead to unsafe use, citing a participant who reported 'she can sit for one or two hours and look at photos or review the main page again and again, checking for new posts' (p. 411).

**Fear and Uncertainty Relating to Social Media Posts** For the most part, uncertainty about posts on social media related to strangers encountered online, inappropriate use, weird posts, unwanted contact, and posts with negative social outcomes

on the person with disability. Raghavendra et al. [12] reported that some participants with disability 'expressed concern about talking to new people online and feared that people might behave unpleasantly towards them' (p. 119). The negative social impact of posts also created uncertainty. While considering social media to be problematic (e.g., in relation to unwanted contact or harmful content), people with disability reported controlling this and making decisions about friend requests based on their impressions of the content posted [27]. Fear of hacking by people not known to them also made some people with disability wary of friending new people: 'all my information is in here …other people might hack my account and fraudulently post it. That is the unsafe part' [27] (p. 417). Chadwick [23] reported that four participants 'spoke about being confused by the behaviour of others online and being unsure how to interact and express themselves appropriately on social media' (n.p.). The authors also reported that one adult with ID opted out of social media in self-imposed digital exclusion due to 'worry and fears about possible risks' (n.p.) and another opted out of Facebook use due to a friend's negative experience 'he was on Facebook and he had threatened, threatened message … and that's why I don't like about it … I can't trust it. I don't like it' (n.p.).

**Unwanted Contact and 'Weird' Content** As a participant with communication disability reported in Caron and Light [21], 'the worst thing about social media is sometimes people use it inappropriately. Some people use it to pick on others and to make them feel hurt. I try to block those people'. (p. 35). Another participant reported that '[T]he bad thing about social media is that people you don't want to talk to or know can contact you. This is annoying. They ask me questions I don't want to answer. If it keeps happening, and I don't know or like them, I block them on Facebook'. (p. 36). Six participants in Kim and Qian [27] felt discomfort in relation to swearing words and slang, as well as 'too many people that I didn't know and there were harmful contents. Weird things. Weird things on Facebook' (p. 418), and another reported weird pictures posted by friends, prompting this participant to delete their account and make a new one, presumably to avoid such content from friends on the network. In the same study, the researchers reported participants drew upon their sense of uncertainty about the content posted in deciding whether to friend or follow a social media user: 'I never request to follow people who post weird stuff on Instagram' (p. 416).

**Negative Impacts on Friendships** Social media use could also impact negatively on friendships, with some people with disability discovering themselves being 'unfriended' (erased from a social network) and becoming aware of this through real-life and somewhat awkward interactions with

friends [18]. Caron and Light [21] reported one participant as stating 'You can post things that upset people and everyone will see it. You need to be careful what you post'. (p. 36). Another participant reported 'I had a bad experience. I got in a big fight with one of my good friends. I posted some things on Facebook that I am not proud I wrote. Everyone saw what I had posted. I felt so bad' (p. 36) The authors also reported lack of direct contact with people as one of the negative aspects of social media use by young people with cerebral palsy; due to preferring in-person contact (particularly to see the person's face while communicating for immediacy and context) or for trustworthiness in the communication: 'people can lie easier online because you don't see them. Talking in person is better because you have to be more honest' (p. 36).

**Negative Comparisons to Others' Posts: Feeling Sad, Frustrated, and Inadequate** Adults with ID admitted to experiencing sadness or jealousy in response to reading social media posts through comparing their own social situation unfavourably: this included feeling inadequate in comparison to others with more followers or reading about other people's romantic relationships and pictures of people dating making the participant 'very sad. I keep thinking why I don't have any friend' and 'I feel jealous that they always eat something I don't get to eat. It doesn't feel great. Travelling, pictures of them travelling are posted a lot and I can't go but they go' (p. 417).

**Multiple Access Barriers and Gatekeeper Restrictions** There is some evidence to suggest that while social media is associated with several benefits, there remains lack of access for many people with developmental communication disability to the internet and social media (e.g., through not having access to technology or necessary supports) and gatekeeping to restrict access to social media. Bosse et al. [19] reported that the main reasons for internet use in adults with complex communication needs were for recreation, social connection, and information; and almost all the participants wished for greater access to the internet for a range of purposes. However, Patrick et al. [28] reported that most of the 370 survey respondents (86.8%) with ID reported not using social media, and that usage (primarily of Facebook and Instagram) was associated with age (59.2% 18–29 years, 28.6^ 30–39 years, 8.2% 40–49 years, 4.1% 50–59 years, and 0% aged 60 + years). Only 56% of participants used mobile devices including tablets and smartphones, and 67% of the non-internet users in the study had unused access to the internet through a computer or laptop at home or other additional options. Overall, there was 'a general desire among participants to use the internet and social media more frequently with a specific focus on mobile devices' [19] (p.1032).

While some studies reported some participants with ID restricting their own use of social media, others also outlined gatekeeping by parents or service providers (e.g., [7]) and disability service providers (e.g., [16, 25]) that impeded the person's access to social media. Shpigelman et al. [16] reported that 6 of 16 family members who did not fully support use of Facebook by their family member or client were concerned about privacy, security, and addiction, as one said 'she doesn't view her Facebook friends as strangers, so she might give them her phone number' (p. 410), with infantilisation 'This is like letting a little kid use Facebook. You don't know who their friends are, what photos they receive or upload, what they tell about themselves. It is scary to think that someone might take advantage of this situation' (p. 410). Another support worker viewed social media as a 'waste of time' (p. 410) in that 'she could be doing sports, improving her reading skills – doing things that could be beneficial for her' (p. 410). Furthermore, while parents and others supporting the person with I/DD attributed their lack of access to the internet being related to the person's limitations (e.g., vision, learning, cognitive, social, and motor) [16, 28], Patrick et al. [28] concluded that '[t]echnology has been and continues to be underutilised by individuals with disabilities and barriers included lack of access, expense, training and support, and device maintenance' (p. 3). Engwall et al. also outlined a range of service-level and policy barriers to people with disability using social media, including lack of internet connections at disability services, passwords to wi-fi only being known by the director, computer can only be used for documentation not by residents, people with ID not having their own email addresses, and lack of access to social media software applications (i.e., security firewall); as well as negative staff attitudes or lack of interest in digital activities, lack of encouragement by staff for the person with disability to engage in digital activities, or not providing the assistance required. The findings underscore the importance of addressing environmental factors (e.g., attitudes of parents and support workers, managers, policies, and funding for equipment) to be addressed and removed to increase access to the internet, including the provision of 'hands-on, interactive components that allow for the development of the required skills as well as meeting daily needs' (p. 4).

## Literacy and Learning in Social Media

A recurring theme across studies was the appearance of literacy (reading and writing) barriers and facilitators impacting on the use of social media. Difficulty with literacy led to uncertainty as to the effectiveness of the person's posts, as one person with disability explained: 'I don't always know the word and know how to spell it. I don't always know if my

posts are okay because of this' [21] (p. 37). Kim and Quan [27] also reported that 'most participants found it difficult to read and write content: "Too many difficult words. It is hard" (Participant 1) and "Uh… When people post something there are things I do not understand" (Participant 1), and "If they use some difficult words, I, don't understand it so…that's a little bit hard" (Participant 7)' (p. 417). However, poor spelling was not always a barrier and 'did not necessarily hinder text communication' [29] (p. 296). One participant said: 'P: It's good. I try to spell but it's difficult sometimes … Those who know me well know what I want to say' (p. 296). Reading news sites linked into social media posts was also difficult due to low accessibility of news websites. Literacy difficulties also meant that people with ID might not post as often, as Shpigelman et al. [16] reported 'He doesn't like to write a lot and his typing is very slow. I assume he knows about the chat function and he does reply to messages that he gets, but he doesn't initiate an online chat' and 'She writes short posts; she mainly uploads photos and then writes the place where each photo was taken' [16] (p. 411). Problems with text meant that participants with ID were perceived to prefer visual-based functions (photos and videos). Some people with disability obtained assistance from other people to overcome the literacy barriers, help with reading or writing text, but 'when help was not available, participants would simply not read the problematic text' [27] (p. 417) or ask someone else (e.g., a trusted friend) what they thought. However, the use of assistive technologies (e.g., speech to text) to create written messages could also improve access to social media, for both writing and reading of content, and remove the reliance on family members for literacy assistance Raghavendra et al., [12] reported that 'Participants found that their spelling difficulties no longer required them to obtain assistance from family members, as the technology supported their independent communication online' (p. 118).

### Implications for Interventions to Improve Social Media Use and Safety

While safety and risk have been the focus of recent social media research, several studies reviewed in this paper uncover evidence that perceptions of risk or harm in using social media are not necessarily seen in the realities of social media experiences—at least for participants with mild or moderate ID. Such risks are recognised as inherent to the nature of social media interactions and not insurmountable by people who also had developed skills in cyber-resilience and safety, signalling increased autonomy and self-determination when encountering the known harms of social media for any users of the platforms. It is not yet known whether the same barriers evidence to accessing social media (i.e., lack of access to technology, skills, funding, supports,

restrictive control, and gatekeeping preventing use) will also impact the access of people with developmental communication disability to GenAI technological advances.

## Limitations and Directions for Future Research

This review of social media research has limitations which mean its findings should be interpreted with caution. It was not a systematic review and included a purposefully selected range of relevant recent literature. Although the studies included met the aims of the review, some relevant studies with divergent findings and yielding additional insights might have been missed. Including only peer-reviewed journal articles, while excluding grey literature, is also a limitation through introducing publication bias.

Nonetheless, the findings of this review reflect that the methodologies selected for recent social media research are diverse as researchers made concerted attempts to obtain the views of participants with developmental communication disability using a variety of methods. The focus and subject matter of the research has expanded to focus not only on views and experiences but also on (a) training people to use social media safely and effectively and (b) the ways that they use social media for social connectedness, self-perception and identity, advocacy, access to information, and sexual expression. However, researchers continue to rely on interviews and surveys reporting on internet or social media use, and there is almost no analysis and reporting of the social media data produced by people with developmental communication disability in research about that use of the platforms. Qualitative findings on social media access and use are rarely triangulated with the social media data posted or read by the participants. Thus, the knowledge base is primarily informed by and reliant on either self-report or the reports of other people on social media usage and experiences. The research questions relating to social media skills and safety issues could be augmented by triangulation with social media data, either posts read by or directed towards people with developmental communication disability, or posts created and published by people with developmental communication disability or co-created and published with their supporters.

### Exploring the Intersection of Generative AI and Social Media

This review highlights multiple facets of two sides ('upside' and 'downside') of social media use by people with developmental communication disability that should be heeded as social media technologies advance alongside and integrated with GenAI technologies. The intersection of social

media and GenAI is important, considering that GenAI is used to (a) drive engagement through personalising content directed towards user preferences and patterns of use of the platforms [10, 30], (b) rapidly generate multimedia content for distribution on social media, and (c) analyse social media data rapidly [31]. However, the peer-reviewed literature does not, to our knowledge, yet include a scholarly overview or guidance on the issues related to the use of GenAI by people with developmental communication disability or in their speech generating devices or other assistive communication technologies. Since 2020, the COVID-19 global pandemic and associated social distancing and lockdown restrictions have stimulated substantial growth in the number of people with disability communicating online [32] for learning, social engagement, connection, and to reduce social isolation [32]. This substantial growth in internet use, including the use of social media for connection, has occurred contemporaneously with rapid development in mainstream artificial intelligence applications, particularly with the release by OpenAI of GenAI software DALL.E in January 2021 (for image generation) and ChatGPT in November 2022 (for generating text) software applications since used by many millions of users worldwide.

These advancements raise important issues when considering the safe use of social media by people with developmental communication disability, given that GenAI applications are now being built into and used in familiar mainstream communication technologies (e.g., internet search engines, word processing software, and social media) [33–35]. While consumers foresee positive uses for GenAI as an assistive technology, they are also cautious and concerned with good reason [36]. There is potential for GenAI to substantially increase the known risks of social media through enabling gamification and highly personalised content generation targeting vulnerable consumers [9]. This relates to the use of text- and image-based AI being used to rapidly generate and propagate misleading information online, driving content and engagement without sufficient human moderation. GenAI could substantially increase the volume of troublesome social media posts (e.g., trolling and cyberbullying), drive increased consumption and exacerbate social media addiction and its impacts [9], increase misinformation or disinformation, lack representation of minority populations, perpetuate health inequalities, and compound disabling attitudes and stereotypes [37–39].

Therefore, future research should explore the access, uptake, and use of GenAI in populations with developmental communication disability and their supporters, including access to the technology and digital literacy demands of GenAI (e.g., prompts and cues and commands) and patterns of use (e.g., editing, publishing, and acknowledging). Legal issues relating to intellectual property and ownership are raised in the use of GenAI to create works to be shared

on social media. Asking people with developmental communication disability about their own experiences creating materials for publication on social media, researchers could focus on how the use of GenAI enhances or disrupts engagement with and enjoyment of social media and any reported benefits. As an example, this review noted that some people with developmental communication disability struggle with reading or writing social media posts, but that this does not necessarily stop them from engaging on the platforms for the sake of connection. This indicates a potential role for GenAI in supporting the literacy aspects of social media use. GenAI could increase access to information, education, or participation online, if it assists in making written information on social media easier to understand (e.g., through translation to easy read material) or produce.

Finally, since a prior call for innovative research [13], there remains a need for research that goes beyond the uptake and use of social media and into the legal and ethical issues confronting users with developmental communication disability and their supporters who have a variety of roles in supporting, enabling, or restricting access to social media platforms and use of the technology. The under-researched areas of inquiry outlined in this paper should therefore stimulate future co-designed research that is more inclusive of people with developmental communication disability on investigator teams so that lived experiences of both the upside and downside of social media can drive further research.

**Declarations**

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# References

1. Statista: Worldwide digital population (2023) https://www.statista.com/statistics/617136/digital-population-worldwide/#:~:text=Worldwide%20digital%20population%202023&text=As%20of%20October%202023%2C%20there,population%2C%20were%20social%20media%20users. Accessed 18 Mar 2024.

2. Caton S, Hatton C, Gillooly A, Oloidi E, Clarke L, Bradshaw J, et al. Online social connections and Internet use among people with intellectual disabilities in the United Kingdom during the COVID-19 pandemic. New Media Soc. 2022. https://doi.org/10.1177/14614448221093762.

3. Borgström Å, Daneback K, Molin M. Young people with intellectual disabilities and social media: A literature review and thematic analysis. Scand J Disabil Res. 2019;21(1):120–40. https://doi.org/10.16993/sjdr.549.

4. Hemsley B, Palmer S, Dann S, Balandin S. Using Twitter to access the human right of communication for people who use Augmentative and Alternative Communication (AAC). Int J Speech Lang Pathol. 2018;20(1):50–8. https://doi.org/10.1080/17549507.2017.1413137.

5. Sweet KA, LeBlanc JK, Stough LM, Sweany NW. Community building and knowledge sharing by individuals with disabilities using social media. J Comput Assist Learn. 2020;36(1):1–11. https://doi.org/10.1111/jcal.12377.

6. Shelton N, Munro N, Keep M, Starling J, Tieu L. Do speech–language therapists support young people with communication disability to use social media? A mixed methods study of professional practices. Int J Lang Commun Disord. 2022;58:848–63. https://doi.org/10.1111/1460-6984.

7. Darragh J, Reynolds L, Ellison C, Bellon M. Let's talk about sex: How people with intellectual disability in Australia engage with online social media and intimate relationships. Cyberpsychology. 2017;11(1Special Issue). https://doi.org/10.5817/CP2017-1-9

8. Office of the eSafety Commissioner. A new playground: The digital lives of young people with disability. Canberra: Australian Government; 2023

9. Greenfield D, Bhavnani S. Social media: Generative AI could harm mental health. Nature. 2023;617(7962):676. https://doi.org/10.1038/d41586-023-01693-8.

10. Keles B, McCrae N, Grealish A. A systematic review: The influence of social media on depression, anxiety and psychological distress in adolescents. Int J Adolesc Youth. 2020;25(1):79–93. https://doi.org/10.1080/02673843.2019.1590851.

11. Grace E, Shipman J, Raghavendra P, McMillan JM. "You got an instant conversation": Goal progress and perceptions following an e-mentoring social media intervention for young people who use augmentative and alternative communication. J Commun Disord. 2023;103. https://doi.org/10.1016/j.jcomdis.2023.106328

12. Raghavendra P, Hutchinson C, Grace E, Wood D, Newman L. "I like talking to people on the computer": Outcomes of a home-based intervention to develop social media skills in youth with disabilities living in rural communities. Res Dev Disabil. 2018;76:110–23. https://doi.org/10.1016/j.ridd.2018.02.012.

13. Hemsley B, Balandin S, Palmer S, Dann S. A call for innovative social media research in the field of augmentative and alternative communication. Augment Altern Commun. 2017;33(1):14–22. https://doi.org/10.1080/07434618.2016.1273386

14. Hong QN, Pluye P, Fàbregues S, Bartlett G, Boardman F, Cargo M, Dagenais P, Gagnon M-P, Griffiths F, Nicolau B, O'Cathain A, Rousseau M-C, Vedel I. Mixed Methods Appraisal Tool (MMAT), version 2018. User Guide. Canadian Intellectual Property Office, Industry Canada; McGill University, Department of Family Medicine, 2018.

15. Patton MQ. Qualitative research & evaluation methods: Integrating theory and practice, fourth edition. 4th ed. Sage Publications Inc; 2014.

16. Shpigelman CN. Leveraging social capital of persons with intellectual disabilities through Facebook participation: The perspectives of family members and direct support staff. Intellect Dev Disabil. 2017;55(6):407–18. https://doi.org/10.1352/1934-9556-55.6.407.

17. Ågren KA, Kjellberg A, Hemmingsson H. Internet opportunities and risks for adolescents with intellectual disabilities: A comparative study of parents' perceptions. Scand J Occup Ther. 2020;27(8):601–13. https://doi.org/10.1080/11038128.2020.1770330.

18. Ågren KA, Hemmingsson H, Kjellberg A. Internet activities and social and community participation among young people with learning disabilities. Br J Learn Disabil. 2023;51(2):125–34. https://doi.org/10.1111/bld.12519.

19. Bosse I, Renner G, Wilkens L. Social media and internet use patterns by adolescents with complex communication needs. Lang Speech Hear Serv Sch. 2020;51(4):1024–36. https://doi.org/10.1044/2020_LSHSS-19-00072.

20. Buchholz M, Ferm U, Holmgren K. Support persons' views on remote communication and social media for people with communicative and cognitive disabilities*. Disabil Rehabil. 2020;42(10):1439–47. https://doi.org/10.1080/09638288.2018.1529827.

21. Caron JG, Light J. Social media experiences of adolescents and young adults with cerebral palsy who use augmentative and alternative communication. Int J Speech Lang Pathol. 2017;19(1):30–42. https://doi.org/10.3109/17549507.2016.1143970.

22. Chadwick DD, Fullwood C. An online life like any other: Identity, self-determination, and social networking among adults with intellectual disabilities. Cyberpsychol Behav Soc Netw. 2018;21(1):56–64. https://doi.org/10.1089/cyber.2016.0689.

23. Chadwick DD. "You want to know that you're safe": Experiences of risk, restriction and resilience online among people with an intellectual disability. Cyberpsychology. 2022;16(3). https://doi.org/10.5817/CP2022-3-8

24. Dada S, Tonsing K, Goldbart J. Friendship experiences of young adults who use augmentative and alternative communication. Int J Disabil Dev Educ. 2022;69(3):951–75. https://doi.org/10.1080/1034912X.2020.1746246.

25. Engwall K. Online activities for individuals with intellectual disabilities at a day centre in the wake of COVID-19. Br J Learn Disabil. 2023;51(2):229–37. https://doi.org/10.1111/bld.12512.

26. Grace E, Raghavendra P, McMillan JM. Gunson JS Exploring participation experiences of youth who use AAC in social media settings: Impact of an e-mentoring intervention. AAC: Augmentative and Alternative Communication. 2019;35(2):132–41. https://doi.org/10.1080/07434618.2018.1557250.

27. Kim KM, Qian X. 'I feel valued': The experience of social networking site engagement among people with intellectual and developmental disabilities in South Korea. Int J Dev Disabil. 2021;67(6):410–9. https://doi.org/10.1080/20473869.2019.1670007.

28. Patrick PA, Obermeyer I, Xenakis J, Crocitto D, O'Hara DM. Technology and social media use by adult patients with intellectual and/or developmental disabilities. Disabil Health J. 2020;13(1). https://doi.org/10.1016/j.dhjo.2019.100840.

29. Ramsten C, Martin L, Dag M, Hammar LM. Information and communication technology use in daily life among young adults with mild-to-moderate intellectual disability. J Intellect Disabil. 2020;24(3):289–308. https://doi.org/10.1177/1744629518784351.

30. Greenfield D, Bhavnani S. Social media: Generative AI could harm mental health. Nature (London). 2023;617(7962):676. https://doi.org/10.1038/d41586-023-01693-8.

31. Matwin S, Milios A, Prałat P, Soares A, Théberge F. Survey of generative methods for social media analysis. Ithaca: Cornell University Library; 2021. (**arXiv.org**).

32. Rice M Special education teachers' use of technologies during the COVID-19 era (Spring 2020—Fall 2021). TechTrends. 2022;66:310–26

33. Jauhiainen JS, Guerra AG. Generative AI and ChatGPT in school children's education: Evidence from a school lesson. Sustain (Basel, Switzerland). 2023;15(18):14025. https://doi.org/10.3390/su151814025.

34. Bengesi S, El-Sayed H, Sarker MK, Houkpati Y, Irungu J, Oladunni T. Advancements in generative AI: A comprehensive review of GANs, GPT, autoencoders, diffusion model, and transformers. 2023. https://doi.org/10.48550/arxiv.2311.10242

35. Zdravkova K, Krasniqi V, Dalipi F, Ferati M. Cutting-edge communication and learning assistive technologies for disabled children: An artificial intelligence perspective. Frontiers in Artificial Intelligence. 2022;5. https://doi.org/10.3389/frai.2022.970430.

36. Favero M, Tyson A. What the data says about Americans' views of artificial intelligence. https://www.pewresearch.org/short-reads/2023/11/21/what-the-data-says-about-americans-views-of-artificial-intelligence/. 2023. Accessed 18 Mar 2024.

37. Glauser W. AI in health care: Improving outcomes or threatening equity? Can Med Assoc J. 2020;192(1):E21–2. https://doi.org/10.1503/cmaj.1095838.

38. M Fengchun, W Holmes. Guidance for generative AI in education and research. UNESCO. UNESCO Digital Library; 2023. https://unesdoc.unesco.org/ark:/48223/pf0000386693.locale=en2023. Accessed 18 Mar 2024.

39. Lorenz P, Perset K, Berryhill J. Initial policy considerations for generative artificial intelligence: OECD Artificial Intelligence Papers. OECD Publishing; 2023. https://doi.org/10.1787/dee339a8-en